PSYCHONEUROIMMUNOLOGY: A CROSS-CULTURAL, BIOPSYCHOSOCIAL STUDY OF THE ROLE OF PERCEIVED SOCIAL SUPPORT FOR PEOPLE LIVING WITH HIV/AIDS.

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"I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person nor material which has been accepted for the award of any other degree or diploma of the university or other institute of higher learning, except where due acknowledgment has been made in the text.

Aaron Cortes Rojas

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"It is in the shelter of each other that people live“.

~Irish proverb

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Abstract

Background: The immunological as well as the psycho-social impact, of living with HIV/AIDS transform HIV/AIDS into a multidimensional process. Stigma and discrimination against people living with HIV/AIDS (PLWHA) are proposed as hostile scenarios increasing hopelessness and reducing perceived and real social support affecting people's health status. Peer support strategies are proposed as key factors for dealing with this scenario; additionally, socio-cultural variables may determine the provision and perception of social support. **Objectives:** To enhance the understanding of the process of living with HIV/AIDS and the role played by social support and to suggest cooperative strategies for dealing with stigma and discrimination against PLWHA to improve people's health. **Sample and method:** Five studies were conducted studying 37 HIV positive members and non-members of peer support organisations (PSOs) in Chile and England; nine healthcare professionals working with PLWHA; and three spokes persons from PSOs of PLWHA from Romania, England and Chile. **Results:** PSOs of PLWHA, which reflect a cooperative strategy used by PLWHA to deal with stigma and self-provide social support, appear to play an important and underexplored role in PLWHAs' health status; this relationship is also affected by socio-cultural characteristics. A measure of PSS was developed and theoretical analysis lead to a linkage with Maslow's hierarchy of needs. Personality characteristics were found critical for the success of PNI based interventions. **Conclusions:** Living with HIV/AIDS involves psychological and social complications. PSOs are a powerful cooperative strategy improving quality of life and general health; however, further research is needed to establish the real impact of PSOs over HIV+ people. **Implications:** The peer-support strategy of PSOs is a powerful but underused clinical strategy. Healthcare teams and PLWHA may benefit from including this strategy if cooperative work is carried out with PSOs.

List of abbreviations

AIDS: Acquired Immuno-Deficiency Syndrome

ARV: Antiretroviral

ASOSIDA (From Spanish acronym)**:** Assembly of Social Organisations and NGOs with work in HIV/AIDS (Chile)

BHIVA: British HIV Association

CCR5, CXCR4: Co-receptors; make possible the HIV entrance into the lymphocytes

CD4+: Particle on lymphocytes' plasmatic membrane which make possible the HIV entrance to the lymphocyte

CDC: Centers for Disease Control and Prevention

CPAS (From Spanish acronym)**:** Questionnaire of Perceived Social Support

DNA: Deoxyribonucleic acid

ELISA: Enzyme-linked immunosorbent assay; used as standard test for HIV diagnosis

FDC: Functional Dimension of Coping Scale

GFATM: The Global Fund to fight against AIDS, Tuberculosis and Malaria

GLBTTI: Gay, Lesbian, Bisexual, Transgender, Transsexual and Intersex.

HAART: Highly active antiretroviral therapy

HADS: Hospital Anxiety and Depression Scale

HIV: Human Immunodeficiency Virus

HRW: Human Rights Watch

IDU: Intravenous drug user

ISP (from Spanish acronym)**:** Institute of Public Health (Chile)

LTCS: Living together cooperatively strategy

MSM: Men who have sex with men

MINSAL (from Spanish acronym)**:** Health Ministry of Health (Chile)

NAM: National AIDS Map

NGOs: Non-Governmental Organisations

NHS: National Health Service (United Kingdom)

NK: Natural Killer (Immune system cell)

PBMC: Peripheral-blood mononuclear cells

PBSCT: Peripheral blood stem cell transplantation

PCR: Polymerase chain reaction [AMPLICOR®]: test used for counting the number of HIV virus in circulating blood (Viral Load Level)

PLWHA: People living with HIV/AIDS

PNI: Psychoneuroimmunology

PSO: Peer support organisation

PSS: Perceived social support

RNA: Ribonucleic acid

STI: Sexually transmitted infection

SW: Sex worker

TIL: Tumour-infiltrating lymphocytes

THT: Terrence Higgins Trust (United Kingdom)

UN: United Nations

UNAIDS: United Nations programme on HIV/AIDS

UNGASS: United Nations general assembly twenty-sixth special session [Declaration of Commitment on HIV/AIDS]

UNOPA(From Romanian acronym)**:** National Union of organisations of people affected by HIV/AIDS (Romania)

VL (VLL): Viral load (level)

WHO: World Health Organisation

YPLWHA: Young people living with HIV/AIDS

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Introduction

In the medical sciences, the traditional approach when dealing with human health and illness has been the biomedical model. This paradigm, beyond any doubt, has made a contribution to human health (Sheridan, 1994 and Vitetta, 2005). Nevertheless, a growing number of studies concerning the interaction of social, psychological and biological factors have begun to explain illness and especially health from a more systemic point of view (Baum, 1999; Relman, 2002; Brown, 2005; Greer, 2006). These studies are based on the biopsychosocial model (Engel, 1977), where diseases are not only biological hazards, but also biopsychosocial processes. Currently, the biopsychosocial approach and the potential it holds for improving quality of life and life span where the biomedical model has limited impact, has been widely studied and verified; however, it is underused as a clinical strategy.

A strong corpus of research demonstrates the interactions among neuropsychological, social and immunological variables (Taylor, 2003, Brown, 2005; Frick, 2005; Irwin, 2007) and, as a result of these investigations, the relationship of mutual influence between psychological variables such as stress and depression to immunological functioning is clear and unquestionable (Lesserman, 1999). These studies have also established the beneficial results of psychological interventions over physiological operation. Stress and depression have been widely studied in relation to their interactions with neurological and immune systems. Several successful attempts at psychological intervention have been developed based on this knowledge. However, social support as a psychological variable correlated with neuro-immunological variables, and specifically with perceived social support (PSS), requires additional research to achieve the level of understanding that stress and depression

have attained in PNI. Psychological interventions also require further research to achieve a level of understanding that will allow the use of this knowledge as a powerful therapeutic strategy addressed to the modification of physiological parameters.

Based on mathematical (Axelrod, 1981), economic (Nash, 1950), human social evolutionary (Borgerhoff, 1988; Richerson, 1997; McDade, 2003), and physiological evolutionary models (Maturana, 1987, 1988; Campbell, 2006), 'living together cooperatively' is proposed as an inherited survival strategy that provides individuals themselves with feelings of safety based on social support. Successfully providing social support is understood to have strong effects on individuals' physiology; this would explain, for instance, the reported beneficial effects on health of social support (Sepa, 2002; Turner-Cobb, 2004; Lutgendorf, 2005). Due to social stigma affecting people living with human immunodeficiency virus (HIV) or acquired immunodeficiency syndrome (AIDS) (Piot, 2000), social support predominates among other psychological variables in HIV/AIDS (Cortés, 2003). In order to provide themselves with social support, people living with HIV/AIDS (PLWHA) have created PSO to deal with the rupture of social support (Parker, 2003; Liamputtong, 2009) and social isolation (Simbayi, 2007). Because of this, the process of living with HIV/AIDS presents favourable characteristics for studying the impact on health of living together as a cooperative strategy for social support self-provision. In this way, and based on the extensive literature on anxiety (understood as stress effect, different from person to person) and depression, social support, and specifically PSS, becomes the key variable for the present PhD research project.

Several questions which arose from these hypotheses are analysed across this PhD project: What the effects of peer support organisations (PSOs) and psychosocial interventions on PLWHA are; Is there any difference in the self-provision of social support across countries? How effective are these strategies for self-provision of social support? How do cultural differences determine the chosen strategies and its effectiveness? What are the effects on health, if any, of these strategies? How are psychosocial and immunological variables related in HIV/AIDS? How are social and health support provided by society and perceived by PLWHA? and How does this provided-perceived relationship relates to socio-cultural factors and to health status in the process of living with HIV/AIDS?.

This PhD aims to broaden the extant understanding about the role of perceived social support (PSS) in the process of living with HIV/AIDS from a holistic and cross-cultural perspective, including two methodological approaches defining five studies over three different samples: PLWHA, directors of PSO and healthcare professionals in England, Chile and Romania.

1) Qualitative approach: Based on social support theory and the study of the psycho-social impact of living with HIV/AIDS, and taking into consideration the scant research on the health impact of peer support as a strategy for the self-provision of social support in HIV/AIDS, this PhD project explores the use of these strategies as used by PLWHA, as well as the support provided by healthcare teams. To this end a) directors of PSOs and b) medical team members were interviewed in different countries:

a) A study of cross-cultural aspects of HIV/AIDS (Chapter Four): This study was conducted in order to achieve a greater understanding of the opportunities for support that PLWHA have in Chile, England and

Romania. It also aimed to study the role played by PSO as a provider of social support and the impact of socio-cultural variables in the process of living with HIV/AIDS. To this end, representatives of the main PSOs of PLWHA in England, Romania and Chile were interviewed regarding organisational starting points, aims, missions and strategies for social support provision. Additionally, several reports by and websites of international organisations which work in HIV/AIDS were consulted.

b) An approach to health professionals' views of HIV/AIDS (Chapter Five): To explore the strategies used to provide medical and social support, and in order to understand 'living with HIV' from the perspective of healthcare teams, nine health professionals, medical doctors, psychologists, social workers and a biochemist from three medical teams were consulted in the three countries.

2) Quantitative: Based on the extensive literature which supports the psychoneuroimmunological approach (Ader, 1970, 1979; 2000; Felten, 1988; Romano, 1991), the significant role of anxiety(Jones, 1995; Kemppainen, 2003), depression (Crook, 2005; Jin, 2006) and coping strategies (Fife, 2008; Farber, 2010) and the hypothesised central role of perceived social support (Hough, 2005; Mak, 2007) in HIV/AIDS were examined; these variables were: a) evaluated in a sample of PLWHA and b)included in the design of a Psychosocial Intervention Programme piloted during this PhD project. Additionally c) a Case report which arose from the Pilot experience is presented.

a) Psycho-immune assessment of PLWHA (detailed in Chapter Six): In order to study how PSS and immunological variables are expressed in

a sample of PLWHA, five evaluations (including PSS, anxiety, depression, coping strategies, immune levels [CD4+] and viral load level [VLL]) were performed in Chile over one year. It was not possible to instrument a similar study in the UK; see details in Chapter Six.

b) Pilot application of a 'Psychosocial Intervention Programme' (Chapter Seven). Based on the available literature and hypotheses described above, a psychological intervention aiming to improve health status of PLWHA was piloted. The aim of this pilot was to test and adapt the Intervention Programme and to learn from the experience of contact with PLWHA members of a PSO in England. The Intervention was based on PSS, and its objectives were as follows:

– The improvement of individuals' abilities to take the most advantage of the support provided by their social networks

– Based on this, for those individuals to have better resources for dealing with depression and anxiety caused by stress,

– To improve these individuals' use of coping strategies.

The intervention started with a psychological and immunological baseline in PSS, anxiety, depression, coping strategies, immune activation (CD4+ lymphocytes counts) and VLL. Post-intervention measures were also taken.

c) A case report (detailed in Chapter Eight): This case details the potential for significant psychological and immunological benefits as a product of the Intervention Programme. After the pilot application of the Intervention Programme, one of the participants reported a remarkable increase in immune activation level (CD4+ lymphocytes count); positive long term effects on psychological and immunological

variables (evaluations after two years); and significant improvements in the perception of the support provided by her social networks. A deeper analysis was conducted to study the possible relationship between immune activation and participation in the Intervention Programme.

PSO of PLWHA are well established in many countries and have been an important source of information, legal advocacy and emotional and psychological support both for members and for society as a whole. They have also promoted a more comprehensive understanding of what living with HIV/AIDS means. For many PLWHA PSOs constitute their most important—or only—social network. However, there are no data concerning possible health benefits among PLWHA as a result of their membership of such groups. This research aims to contribute to the understanding of psychoimmune relationships and possible immunological benefits of psychological interventions and PSO membership. This information may change the perception of PSO as a booster of PLWHA health status.

Chapter One: Social support and cooperative strategies in HIV/AIDS

The biopsychosocial approach provides both the base and guidelines for this PhD project. This research focuses on the potential for benefit to the health status of PLWHA based on a psychoneuroimmunological approach in healthcare centred in provided and perceived social support. Rooted in evolutionary models proposing physiological modifications in people's interaction with their environment (epigenesis: Maturana 1987, 1988), as well as the theory of cooperative work (Axelrod, 1981: cooperative-self-benefit dilemma and Nash's equilibrium theory, 1950) it is proposed that 'living together cooperatively' is an inherited survival strategy. This strategy is also proposed as a tactic for coping with stressful situations and is currently used by individuals as a way of providing themselves with social support. The 'living together cooperatively' strategy is therefore proposed as having direct benefits to one's health status. On the other hand, hostile environments in which some individuals are constantly excluded and discriminated generate behaviours like the ones described by Abramson (1989) which typify hopelessness depression. This PhD studies the dynamic of living with HIV/AIDS from a holistic perspective including a consideration of PSS as the target of a strategy of 'living together cooperatively', and aims to broaden the understanding of this process. The researcher also developed a Psychosocial Intervention Programme based on PSS which aims to modify psychosocial variables and immunological parameters.

Across this Chapter the theories related to these areas are described, the need for this research is explained and the targets are settled. At the end

of this Chapter the research questions guiding this research project are presented.

1.1. Living together: An epigenetic, cooperative strategy for social support provision

This section puts forth the main theories and states the hypothesis of this PhD project, establishing a frame by which to achieve a wider understanding of the effects on health of PSS in people living with HIV/AIDS (PLWHA). First, the theory and approaches in social support and specific to PSS are described. Second, theories and research about the correlation between psychosocial and immunological variables are summarised and analysed including theorisations about cooperative strategies and evolutionary processes. Although the description of the evolutionary process is outside of the scope of this PhD research, further description and specific evidence concerning PSS and its relation to human evolution might be part of post-doctoral follow-up research; with this in mind, a preliminary theorisation about an epistemological base for cooperative strategies related to social support is presented. Anxiety (Antoni, 2000), depression (Yirmiya, 2000) and coping strategies (Van den Boom, 1996) have been widely documented in research focused on PNI; therefore, they are briefly described here, and this description focuses on their relation to PSS, as PSS is the key variable for this study.

1.1.1. Perceived social support: theoretical base

The concept of social support has been broadly defined as all positive interaction provided to a person in need of support (Rook & Dooley 1985). The concept has been theorised and defined in different ways complicating its measurement. However, when defining social support, the literature

often incorporates concepts such as emotional support; instrumental or tangible support; informational support or affirmation; and companionship, comparison or appraisal support (Agneessens, 2006; Bogossian, 2007). Additionally, the existing theory around this concept allows empirical research (Rees, 2007). Hupcey (1998) proposed a useful categorisation of the theoretical definitions of social support:

1) Social networks: This category conceptualises social support by its accessibility through social links: individuals, groups, communities, etc. (Lin, 1979). This categorisation has been the most used and studied.

2) Type of support. This refers to the resources provided by one person to another (external perspective, Cohen, 1985) and the information a person receives that forms his/her idea or belief that he/she is loved and appreciated. This information allows the person to locate him/herself as member of a network (internal perspective, Cobb, 1976)

3) Perceived support. This refers to the level of satisfaction that a person has as related to his/her need for support, information and reciprocity (Procidano and Heller, 1983).

4) The intention of the provider of support. This is defined as an exchange of resources, with the idea that the given resources will improve the recipient's well-being (Shumaker and Brownell, 1984).

5) Reciprocity. This category states that the function of social support is the exchange between a provider and a receiver (Antonucci, 1985).

These categories or types of social support provide the base for modern definitions of this construct, which is focused more on the receiver's

perception of the offered support. It is anticipated that each individual would expect different types of support from different networks; therefore, emotional support would be primarily expected from family or friends, while information might be expected from any institutional network. However, this can vary since different individuals expect different support from their networks.

Accordingly, social support can be offered by any network, but how this support is perceived will be determined by the degree to which the individual's needs are satisfied in the interaction with his/her social networks (Bogossian, 2007). To this definition it is necessary to add the degree of needs the individual has. These needs will determine how gratifying these social interactions are perceived to be. In this way, the resulting satisfaction from the support available is related to perceived support, but depends on the support needed (Dunkel-Schetter and Bennett, 1990). Additionally, coping strategies to deal with stressful situations will determine the level of support needed and will then influence the perception of the support available.

Broadly, social support includes three main constructs: supportive networks, supportive behaviours and support as an emotional construct (Cohen, 1992). Following this conceptualisation, social support evaluations should consider—as a minimum—three areas: 1) social networks, 2) perceived support and 3) supportive behaviours; in addition, the evaluation might also include instrumental support.

The concept of *social networks* has been conceptualised as: *The currently significant group of people with whom the individual has social interactions* (Flores and Ibache, 2002).

More broadly, institutions having regular contact with individuals are also included within the category of supporting social networks. Social support is always an interaction in a 'providing-receiving' dynamic, and its effectiveness (judgement of how supportive the networks are) is always dependent on the recipient's perception.

Bogossian (2007) describes the different types of support as follows:

Emotional support *consists of intimacy and attachment, reassurance and confiding in and relying on one another. It implies a caring relationship or membership of a group and may be as simple as a willingness to listen or companionship.*

Informational support *involves the provision of information or advice to assist the person in solving a problem and providing feedback on how the person is doing. Feedback assists the person to maintain social identity, provides a sense of social integration and control, and increases confidence and security.*

Tangible support *addresses the provision of practical help and encompasses a broad range of activities. It focuses on direct aid or services which can include loans, gifts, taking care of a needy person or assistance with chores and other types of more general aid.*

Comparison support *relates to encouragement, advice or information given by someone in a similar situation or who has had similar experiences. People providing this type of support are perceived by the recipient to have credible feelings or information to share.*

Based on the above conceptualisations, social networks' performance, people's behaviour, and received support are defined as inevitably perceived, evaluated and interpreted. Therefore, PSS is proposed as the dominant factor regarding the effects of social support on a person's well-being.

Conceptualisations of social support tend to define social support as the way help is given (Sepulveda, 1998). Of equal importance, however, is the fact that negative interactions are stressful (Coyne and DeLongis, 1986) cand have strong effects on well-being (Rook, 1984). Even 'positive support' may be perceived as negative in situations such as these:

– when the help is perceived to have made things worse;

– when the receiver's interpretation of the provider's 'real' intentions is that 'he/she just wants to take advantage';

–when the support comes too late or too soon, creating the feeling that 'nothing can be done now', or 'I just need to be alone';

–when the support is inappropriate, too invasive, or when the receiver feels that the supporter did not understand the problem (Antonucci, 1985).

The effectiveness of supportive networks is defined by the individual's needs for support, as well as his/her perceptions and judgements about that support. It is because of this that compared with any other organisation, peer support groups have incomparable advantages for success: they have similar targets, shared concerns and an understanding of experiences as signs of mutual confidence and identification. These 'natural characteristics' become key elements which ensure 'tailored' strategies for offering social support and improving the health status of their members.

"Networks are social interaction manners defined as a dynamic interchange among people, groups or institutions in a complexity scenario. An open system in a continuous reconstruction involving groups identifying in themselves the same needs and concerns; groups able to organise themselves in order to promote their resources"

Aruguete, 2001 [online]

Sepulveda *et al* (1998) maintain that social support is a key factor for individuals', couples', groups' and families' well-being, especially in times of stress, change or crisis. Social support, which is essentially qualitative, is one of the functional aspects of social networks. It involves variables related to basic functions that networks carry out for their members in order to support them in their adjustment to environmental requirements. However; the possibility of negative support needs to be included. If the structure of the social networks satisfies a person's needs, this will be the key to their well-being; if not it might cause or increase their distress. This depends on the quality of support provided by each network and each individual's interpretations.

Although social networks are related to a socio-structural dimension, and ergo, allow analysis at a social level, which is different, although complementary (Sepulveda, 1998), social support refers to a personal dimension and its more subjective component is the perceived social support (PSS). An individual could, therefore, be defined by their social or group community memberships, which give a basic structure to his or her identity. Nevertheless, the identity of each individual is defined by the author, not only depending on the individual's inclusion in a social group but on the recognition of his or her own membership in multiple communities, on the acceptance of differences and on mutual recognition. Social inclusion is shaped by the interaction and interchange between social groups with common needs and interests. The perception of membership is crucial, more than membership itself. This perception gives peer support groups an essential advantage in terms of commitment, adherence, identification and perceptions of belonging to the group. Perceiving oneself to be a member is related to acceptance and the quality of relationships. Therefore, it is clear that social support and social

networks are separate variables related to different psychological functions (Bogossian, 2007).

Based on the theory available, this research understands social support as crucially defined by its perceived component; the perceived level of satisfaction resulting from any social interaction. Additionally, the level of identification with the group and individuals' level of needs are the point from which to interpret tangible support and social characteristics. In this context, perceived social support becomes the key factor for social interactions and peer support groups have a natural advantage for social support provision. For this definition, concepts such as level of needs and expected support from each network are fundamental.

1.1.2. Social evolution and organic functions

Our physiology is the result of a complex process modulated by continuous adaptations; each part of an organism has been modified to be functional in its specific environment (Haas, 1997). This evolutionary process provides organisms with the necessary flexibility to adapt to their environment. However, that flexibility may take thousands of years to develop when it refers to physiological adaptations, and changes endure even when the causal conditions have disappeared. As a consequence, the adaptations become obsolete, and even detrimental, in new scenarios (Valle, 1999). These adaptations can also influence psychobiological responses; for instance, the physiological stress response, which is extremely effective to deal with acute stressors like predators, is physiological and psychologically harmful when facing chronic stress, like contemporary life complications (Fors, 1999). Those physiological and

behavioural modifications include also immune function (Oyama, 1985; McDade, 2003).

This argument points at the comparatively fast pace of social evolution as compared with human physiological evolution (Borgerhoff, 1988). This leads to the comparison described by Valle (1999) of a modern individual with pre-historic physiology dealing with contemporary stressors.

Axelrod (1981), in his theory of cooperation, states that individuals can behave cooperatively for a higher prize, and described 'Tit For Tat' as the most successful strategy in group cooperation when compared with self-benefit dilemma. This strategy presumes cooperative work with the outcome of the cooperation being better for the group. Emerging from the field of economics, Nash's equilibrium theory (1950) sustains that even when a population uses non-cooperative or individual work, even if they are not aware of it, there will always be an equilibrium point where communal benefit will persist. He further argues that individuals accumulate experience and as a result they become cooperative. These theories have been used in evolutionary biology to explain cooperative behaviours.

Hence, a cooperative strategy to face their environment was the most useful solution for our ancestors; those who learned how to live in groups and cooperate had a higher likelihood of successful hunting, finding better places to live, staying alive and even feeling safe. In other words, living together cooperatively was the strategy that allowed our ancestors to pass on that very lifestyle. Here, group selection is the most likely situation; patterns of in-group cooperation and out-group hostility gave rise to some kinds of cognitive capacities, emotional answers and sheltering feelings

(Richerson, 1997). That interaction may have provided the basis for cultural transmission, identity and cooperative groups present in our society; this strategy of 'living together cooperatively' is proposed in direct lineage with modern social support in a process involving sociological evolution and physiological natural selection. As for stress responses, it is proposed that the strategy of 'living together cooperatively' meant physiological changes for the members of the group, who would then confer the genetic predisposition to form cooperative groups, herds, tribes and families in order to provide a supportive social environment. This is interpreted as a strategy rooted in the evolutionary process: individuals who chose to live together cooperatively and learned social cooperative behaviours had higher possibilities of survival. The inheritance of this strategy is proposed as the foundation for the establishment of communitarian life with psycho-bio-social effects. This hypothesis visualises the advantages proposed for peer support groups and their impact on the health (biological and psychological) of their members from an evolutionary perspective.

The second main concept adopted in this PhD thesis is the relationship between psychological variables and immune, endocrine and neurological systems, also known as the neuro-immune-endocrine network (Jadresic, 1993; Ader, 1995; Berczi, 1998; Yang, 2000; Reul, 2005). Studies have demonstrated this interaction in numerous areas, such as the psychological influence on cancer evolution (Delgado, 1989; Blasco, 1990; De la Parra, 1991; Reiche, 2004), general health and psychology (Casado, 1996), sexual dysfunction and psychiatric morbidity (Catalán, 1981), brain changes based on the social environment (Valencia-Alfonso, 2004), immunological changes related to social support in asthmatic children (Canelones 1999), the effects of stress (Cornejo De Luigi 1986) and

depression (Carvajal, 1994) on the immune system, the effects on retardation of healing under stress conditions (Kiecolt-Glaser 2002), reduction of cardiovascular activity and heart rate in individuals in a more supportive social schemas (Ratnasingam, 2007), and the effects of neuroendocrine stress hormones over the production of interleukin-10 which have inhibitory effects on NK cytotoxicity activity (Lutgendorf, 2005). All these studies have a holistic perspective; psychoneuroimmunology (PNI) has been the platform for systemically studying humankind (Ader, 1995; Haas, 1997; Fors, 1999) and for acquiring a more sophisticated understanding of the complex interactions between an organism and its environment.

The environment can strongly affect individuals' behaviour and the range of possible responses to stressors. Seligman (1967) described in animal models how non-responsive behaviours to situations that would seem to demand an avoidance of punishment can be imposed by unavoidable, traumatic environments. The learned helplessness theory was described in humans (Abramson & Seligman, 1978) and later identified as a specific type of clinical depression called hopelessness depression (Abramson, 1989). A subject facing adverse results may keep trying; nevertheless, this insistence should be realistic or it may cause higher anxiety, affecting adaptation abilities. Facing a constant period of frustration may generate feelings of loss of control which are difficult to change; these feelings may cause depression, situating the person as a 'victim' of the environment, the 'learned hopelessness' which causes the lack of motivation to answer to the environment. This stage induces particularly negative feelings, thoughts and unpleasant perceptions of the environment and may represent an acute depressive syndrome.

This theorisation forms the basis for analysing social support from a different perspective and was the proposed frame in which the findings of this PhD were interpreted. With this approach, it is argued that both the specific actions individuals perform to provide themselves with a supporting environment and the events occurring in this environment affect the possibilities of social support and that this will strongly determine both individuals' perception of that support and their subsequent actions undertaken to provide a self-supporting environment, in an endless feedback loop. It is at this point that the hypothesis of *epigenesis* emerges as the most plausible explanation of the 'construction' process of the structure of every organism. This explanation foregrounds the interrelation between experiences and inherited genetic material and development from a pre-existing basis where the environmental stimulus and the genetic information are in a mutual and ancestral relationship (Maturana, 1987). Each resulting behaviour, condition, structure or perception is the result of a continuous chain of changes which itself is the product of countless interactions with the environment (Maturana, 1988). This presents the possibility of development and change as an always available constant. The results of the strategies used to deal with environmental obstacles will determine whether a specific situation is perceived as a threat or just a daily incident. Anxiety caused by stress, depression or low PSS are responses affected by the result of specific styles of interpreting the environment, and, coupled with environmental conditions, determine the sort of interactions an individual has. Additionally, as feedback, these responses determine the individual's environment (Hernandez, 1997). These interactions also determine psychological and physiological operations. For example, positive affective styles of interactions have been associated with better immune functioning compared with individuals characterised by negative affective styles (Barak, 2006). However, the

effects of continuous adverse environmental conditions can have extremely negative effects on individual health, as established by hopelessness depression theory (Abramson, 1989). The widely documented scenario of social stigma and discrimination against PLWHA and the variety of psychological afflictions commonly associated with HIV/AIDS are a perfect example of Abramson (1989) description.

Based on holistic perspectives, such as the biopsychosocial approach and psychoneuroimmunology (PNI); mathematic and economics theories like Axelrod's (1981) Theory of Cooperation and Nash's (1950) Equilibrium Theory; Evolutionary Epigenetic Theory (Maturana, 1987); and hopelessness depression theory (Abramson, 1989) this research proposes a *living together cooperatively strategy* (LTCS) as an evolutionary outcome used to self-provide support from social networks. This strategy is proposed as influencing PSS, group membership feelings and immune system functioning. Additionally, PSOs are hypothesised as one example of LTCS. This PhD asks how PSS and the strategies used by individuals to provide themselves with social support influence those individuals' health status, specifically as regards immunological variations, and whether group membership might be a factor influencing these relationships. In other words: How important are these interactions? To what extent does PSS influence the commonly described correlations between physiological and psychological parameters, such as depression and anxiety? Are these correlations related to bodily functioning?

In order to obtain data regarding this under-explored area, five studies were undertaken analysing the process of living with HIV/AIDS in Romania, England and Chile.

The next section will describe the populations and variables studied with the aim of answering the described questions and establish the specific area to which this PhD contributes complementary knowledge from the PNI perspective.

1.2. Living with HIV/AIDS and signs of hopelessness

To tackle the established aims, the process of living with HIV/AIDS was studied from various perspectives from England, Romania and Chile. PLWHA, PSOs and healthcare team members were included in the study. PSS, anxiety, depression, coping strategies (approach, avoidance, emotional regulation and reappraisal), viral load level and immune activation level (CD4+ lymphocytes) were included as variables.

Prior to a review of literature about PNI and HIV/AIDS in a cross-cultural view, some general definitions about HIV/AIDS are presented in order to familiarise the reader with specific terms and basic information necessary for the analysis which will follow.

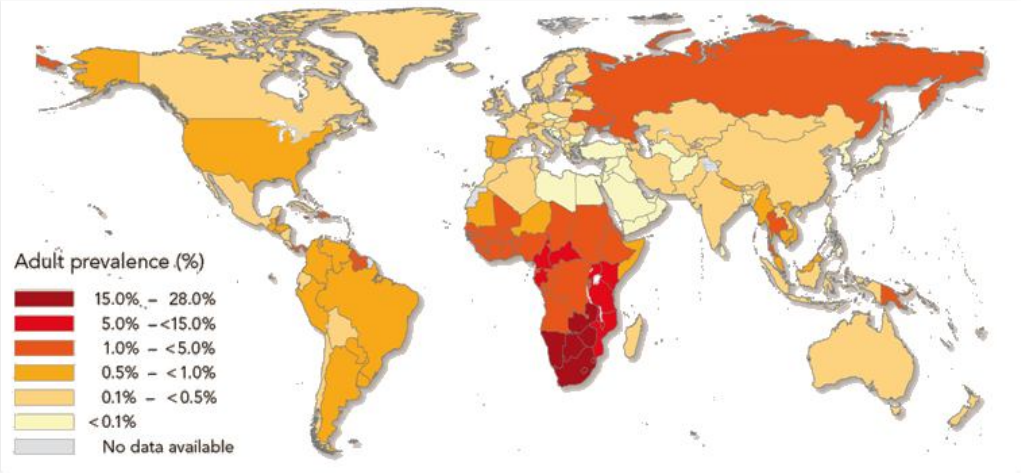
1.2.1. HIV and AIDS; epidemic of a immune disease

AIDS is the acquired immune deficiency syndrome caused by the acquisition of the human immunodeficiency virus (HIV). The AIDS stage is characterised by a decrease under 200 CD4+ lymphocytes/m^3 in circulating blood.

The HIV virus is divided into two main groups, HIV-1 and HIV-2. Specific antigens (proteins) in the exterior of the virus enable it to attach itself and infect cells with the CD4+ particle on its plasmatic membrane (exterior). The CCR5 and CXCR4 acts as co-receptors and are necessary for the virus

to enter the cell. The main cell having these characteristics is one of the most important cells of the immune system, the CD4+ lymphocytes. During the HIV infection, the CD4+ lymphocytes, normally in ranges of 800 to 1200 cells/m³, suffer a progressive detriment and usually stabilise around 500 cells/m³ (Sepulveda, 2002).

The last report from the United Nations (2008) states that the epidemic has been stabilised. An estimation of 33 million PLWHA was made for 2007; of these, 29.7 million were adults, 14.1 million were women and two million were children younger than 15.



Source: United Nations Programme on AIV/AIDS [UNAIDS], 2008
Figure 1.1: HIV/AIDS Adult percentage prevalence worldwide.

Figure 1.1 shows the percentage prevalence of HIV/AIDS for 2008. Despite of high rates of acquisition, global numbers have decreased since 2003. The number of women living with the virus has stabilised to around 50% of the total cases. Twenty-five million people have died because of AIDS since the first case in 1979.

The natural evolution of the HIV infection has four stages (details in Appendix C). Table 1.1 presents the codes given by the Centres for Disease Control and Prevention (CDC) to define these stages. In terms of

management the highly active antiretroviral therapy (HAART), composed of several antiretrovirals (ARV) is, so far, the most effective way to treat HIV/AIDS. Each ARV acts in a different stage of the HIV replication process. Latest ARV acts in the moment of the fusion (entrance) of the HIV with the lymphocyte. Details of this process are outside of the scope of this research, but a simplified summary with the more relevant information is presented in Appendix D. The HAART reduces the number of virus circulating in the blood to undetectable ranges; however, the virus is not eliminated from the body. In fact, the VLL is always growing due to the fact that the main reservoirs of virus are in the glands and bone marrow, where the ARV have no effect. In most cases, and as a side effect to the reduction of circulating virus, the CD4+ lymphocytes start to rise in numbers, stabilising at around 500 cell/m^3.

Table 1.1 CDC Classification System for HIV-Infected Adults and Adolescents

	Clinical Categories		
	A	**B**	**C**
CD4 Cell Categories	**Asymptomatic, Acute HIV, or PGL**	**Symptomatic Conditions,#* not A or C**	**AIDS-Indicator Conditions***
(1) ≥500 cells/µL	A1	B1	C1
(2) 200-499 cells/µL	A2	B2	C2
(3) <200 cells/µL	A3	B3	C3

Key to abbreviations: CDC = U.S. Centres for Disease Control and Prevention; PGL = persistent generalized lymphadenopathy.
#* For symptomatic conditions, see appendix A
*For AIDS-indicator conditions, see appendix B

Source: CDC, 2009

A cure has not been found yet; however, recent research may change this. As mentioned HIV needs the receptor (CD4+) and co-receptors (the chemokines CCR5 or CXCR4) in order to be able to infect the host cell and start reproducing itself. Approximately 1% of the population has a deletion of these chemokines; this confers total or partial resistance to acquisition

of HIV. Hütter (2009) studied the effects of the CCR5 co-receptor and performed marrow bone transplant from a HIV- (negative) donor with a deletion in the CCR5 co-receptor to a HIV+ person. By doing this, Hütter succeeded in transferring the CCR5 deletion from the donor to the HIV+ patient. As a result, the patient has maintained his condition without signs of the HIV virus after 20 months of the transplantation (the point the results were published), while HAART has been suspended since the surgery. Despite the difficulties in finding a compatible bone marrow HIV- donor who additionally has CCR5 deletion, and despite the fact of a second co-receptor (the CXCR4, which was not present in the case presented by Hütter) this study opens a promising area of study for an HIV cure.

1.2.2. HIV/AIDS: the psycho-social disease

A brief description of HIV/AIDS has now been presented; however, for the purposes of this research project, the most important factor related to HIV/AIDS is its psycho-social impact.

From the discovery of the first cases, strong stigma about the disease's 'moral' connotations has been attached to HIV/AIDS. This led to the establishment of the fight against stigma and discrimination being one of the main goals subscribed for almost every country in the globe (UNGASS, Political declaration: 2006).

The effects of the unfavourable environment for PLWHA have been reported in several psychological afflictions in PLWHA, having higher incidence of depression (Eisenberg, 2003), stress (Robinson, 2000) and lower social support (Fekete, 2009) as compared with the general

population (Singleton, 2000, MINSAL[1], 2006). This incidence can be understood by considering the pathological process of hopelessness depression (Abramson, 1989) and the negative effects on personality of stigma and isolation (Goffman, 1963), currently linked to stigma and the consequent rupture of social networks suffered by PLWHA (Parker, 2003). In addition, Simbayi (2007, p. 1824) maintains that AIDS stigma and social network rupture also interfere with HIV prevention, diagnosis and treatment. Stigma and discrimination against PLWHA can lead to learned hopelessness behaviours resulting of continuous exposition to such adverse contexts.

Supportive networks such as those found in churches, schools, universities, any social institution, or even the city or country where people live give identity and define social behaviours. These networks are also responsible for *instrumental* and *informational support* and *social companionship*. Emotionally closer to the individual are *social networks*, including family, close friends and partners; *social networks* are responsible for *emotional support* and *appraisal support* and *social companionship* can be found in *social networks* and *supportive networks* (Bennett, 2001). However, there is a third transversal component, the PSS, which refers to how much support a person believes to have been provided by supportive and social networks (Bogossian, 2007). Therefore, if supportive and social networks do not provide enough companionship, emotional support, appraisal, instrumental and informational support the possibilities for distress distension and release of emotional tension are strongly limited. This process is proposed as one of the most important factors in stress and depression observed among PLWHA. Studies suggest that poor levels of PSS mean a higher rate of psychological afflictions and physical symptoms

[1] Health Ministry [Ministerio de Salud] of Chile.

in PLWHA, compared with patients perceiving their social networks more supportive. Additionally, PSS showed higher correlations with immunological parameters compared with stress and depression (Cortés, 2003).

PSS acts as mediating variable between immune responses, stress and depression. This is coherent with the proposed 'living together cooperatively strategy', since the effects of having a supportive network acts as a tension releaser. For instance, stress is defined as an acute (immediate) response that involves metabolic, physical, cognitive and affective aspects when an individual is dealing with an over demanding situation. Nevertheless, the stress response is not damaging *per se*; it is the distress response (chronic, delayed, and persistent) which causes damage (Valle, 1999). This response refers to an unadjusted and persistent stress. The individual's capacity to respond and to adapt to stressful situations determines, therefore, the levels of anxiety and the presence of distress symptoms. If the environment is supportive and helpful, the perception of personal self-efficacy to cope with the distressing situation will be adequate and the distress effects lower. The same logic applies for depression described as a mental disorder that includes depressed mood, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, low energy, and poor concentration. These symptoms can be chronic or recurrent and can seriously affect the ability of the individual to take care of responsibilities or of him/herself (WHO, n. d. [online]).

Depression is characterised by a progressive deterioration process; in that process social networks play a crucial role and, once again, the support

provided by the environment is proposed as a prophylactic and therapeutic factor.

In the study of HIV/AIDS, social support, stress and depression have been linked with immunological and virologic factors. Robinson (2000) sustains that there is enough evidence sustaining the correlation between these variables confirming the positive effects of psycho-social interventions on immunological indices in HIV/AIDS.

Due to their significant role in immunological responses, the number and percentage of CD4+ lymphocytes are commonly used to indicate the level of activation of the immune system and HIV/AIDS progression. This immunological factor has also been related to social support. For instance, Eisenberger (2003) found in a sample of 61 HIV+ women that the level of emotional inhibition (as a reference of how supportive networks are perceived) was negatively correlated with the number of CD4+. Another clinical parameter in HIV/AIDS linked with social support (Feteke, 2009) is the VLL, which is the number of (HIV) virus/µL in circulating blood, and is another of the standard indicators of HIV progression and a direct index of the effectiveness of treatment (National AIDS Map, 2009 [online]).

1.3. PNI and HIV/AIDS

The main hypotheses and the supporting theory; the goals, the targeted population and the specific area of study; and the most important and most studied variables in the process of living with HIV/AIDS have been established and described. In this section, key studies about the interaction between the described psychological, social and immunological factors are detailed to give more context and grounding to the present research.

Based on studies proving the genetically inheritable condition of specific survival behaviours, mainly located in the limbic system, and specifically in the cerebral amygdala (Haas, 1997) and on the proposition of the inherited origins of the capacity of living together and working cooperatively as a survival strategy, it is argued that the development of social behaviours has a bio-psycho-social background. The body of evidence establishing the relationship between physiological and psycho-social variables is the base for this hypothesis. For instance, the verbal self-disclosure of traumatic situations has been associated with beneficial cellular immune responses. Sherman (2000) studied 64 children living with HIV, along with their caregivers, and found better immune responses, expressed in significantly higher CD4+ lymphocytes counts among children who had disclosed their HIV diagnosis to their friends. In the same way, gay men concealing their homosexual identity have a higher incidence of cancer and other infectious diseases compared with those 'out of the closet' (Cole, 1996; Ullrich, 2003). The disclosure effect may be mediated by the possibility of better quality support provided by the networks once they know what had been concealed and was affecting the person. Pressman et al (2005) studied 83 university students and found that social networks were associated with antibody response to the influenza vaccine; among students who showed higher levels of loneliness there was lower antibody response and higher levels of stress. None of these results were associated with the size of the social network concerned; in other words, the support provided by the networks was more significant than the number of people or networks involved. This reflects the importance of the PSS (quality) over the number of networks or their size (quantity). Similar findings were published by Turner-Cobb et al (2000) studying the levels of salivary cortisol in 103 women with metastatic breast cancer and the quality (appraisal, belonging, tangible support and self-esteem) and quantity (number of people) of

social support. Again no correlations were found between the quantity of social support and the neuroendocrine indicator (cortisol), but inverse correlations were found between the quality of social support and the level of salivary cortisol, indicating better neuroendocrine functioning among people better supported.

An interesting analogy between cellular and individuals' behaviour can be done based on Lutgendorf's (2005) study; a group of 42 participants suffering from ovarian cancer and 23 having benign pelvic masses were analysed. Lutgendorf found that participants with higher levels of social support had significantly higher Natural Killer (NK) cytotoxicity (a qualitative indicator of cells' efficacy) in both peripheral-blood mononuclear cells and tumour-infiltrating lymphocytes; however, the level of social support was not correlated with the percentage of NK cells (a quantitative indicator). Social support, then, may have a higher correlation with the effectiveness of NK cells, in other words with quality rather than quantity. In the same way, it is the quality—the PSS—which has the highest correlations with physiological functioning, not the number of social networks or people offering support. Thus, in both cases it is the quality, either of the effectiveness of the NK or of that of the PSS, which is related to wellness.

Similarly, study results of 54 post-operative breast cancer patients' levels of optimism were correlated with NK cell activity (Von Ah, 2007). These studies show a relationship between immunological response and PSS. However, in another study of PSS as a survival predictor after peripheral blood stem cell transplantation (PBSCT) the researcher did not find an association between positive interaction and survival among these patients. Nevertheless, the researcher did find an association between poor survival

and problematic PSS after PBSCT (Frick et al, 2005). This research may indicate that PSS could be a “prophylactic” strategy used to prevent problems rather than a therapeutic tool used to help in the solution of problems. However, Frick et al (2005) used a social support scale which only measured PSS related to the illness and the changes that this condition may cause and less related to ‘general PSS’ in areas such as identity, belonging and acceptance. In order to make this argument clearer, the cited research concerning the disclosure of HIV diagnosis may help. Sherman et al (2000), found that among long-term survivor children living with HIV who disclosed their diagnosis to friends early in its process showed a strong rise in the percentage of CD4+ as compared with children who had disclosed their diagnosis later or those who had not yet told anyone of their diagnosis. O’Cleirigh (2003) partially explains these results. In a sample of 135 PLWHA, emotional expression and depth of processing of trauma about HIV/AIDS were negatively correlated to viral load level and positively correlated to CD4+ and long-term survival; however, this relationship was mediated by the depth of processing of trauma. PSS and stress were correlated with the depth of processing of trauma, but not with emotional expression. This may be related to self-disclosure and the quality of social networks in facilitating processing of trauma and reducing stress levels; the fact of having a ‘secret’ from the peer group turns the secret holder into someone different from the group. For example, in the situation of someone living secretly with HIV, the act of disclosing that secret to the peer group restores balance; from that moment all members of the group are ‘equal’ because there is no secret to hide. The PLWHA recovers his or her feeling of belonging to the group. Clearly, negative group reactions to the disclosed information may produce higher levels of distress; however, the feeling of belonging to a peer group, and the opportunity of processing the trauma in depth has psychological and physiological effects. Thus, PSS

evaluations should consider all different dimensions of social support in order to evaluate fully its effects on individuals' health status.

Being diagnosed as HIV+ has been well documented as an extremely stressful situation (Balbin, *1999;* Evans, 2002), which affects immune responses (McCain, 2003; Motivala, 2003). What HIV means for an individual's health status combined with the social stigma associated with the virus (Mak, 2007), involves high risk for depression and stress from the time of diagnosis (Cruess, 2003). Moreover, the adverse effects of stress (Lugendorf, 2005; Robins, 2006), depression (Prachakul, 2007) and lack of social support (Cole, 1996-b; Goodkin, 1998; Ullrich, 2003; Robbins, 2003) on immune system functioning also have been documented.

All this evidence suggests strong correlations between PSS and immune functioning mediated by group interactions, giving support to the hypothesis of 'living together cooperatively strategy' as the inevitable cooperative equilibrium in Nash's (1950) theory; however, how are these processes expressed in daily life? Do they have any effects on an individuals' health? Are they used by people around the world, even if they are not aware of it? Is it possible to combine PNI, the Nash's equilibrium theory, the Axelrod's (1981) theory of cooperation and the proposed 'living together cooperatively strategy' theory to develop an integrative healthcare approach for HIV/AIDS? These are questions which are as yet without answers.

The interactions between people and their environments have different results depending on each individual and his/her specific environment, and strongly depending on individuals' interpretations and common cultural patterns of behaviour. However, there are common factors possible to

detect in any environment. One of these common features is the proposed living together strategy and cooperative work. It is clear that environments influence the life of people living in them; the obvious example is the different customs and cultures around the world. Supportive networks or groups of people sharing similar experiences and knowledge are one of the most used strategies for self-support and networks of PLWHA are common around the world; nevertheless, there are no studies regarding the effects of PSOs of PLWHA in terms of the health status of their members. Related studies have established the effects of peer support in reducing stigma and discrimination within PLWHA (Liamputtong, 2009); the effectiveness of psychological peer group interventions in optimism, adjusted and decreased psychological distress, such as depression and anger associated with AIDS in orphans (Kumakech, 2009); the association of psychological interventions in support groups with reduction of viral load among adolescents with HIV/AIDS in a pilot study (Funck-Brentano, 2005); established the effectiveness of peer support interventions to increase the level of information and reduced stigma in health professionals (Kaponda, 2009); shown efficacy as a preventive strategy for HIV acquisition in youth communities (Maticka-Tyndale, 2009); and have been related to empowering effects in peer support groups of people affected by cancer (Ussher, 2006). Peer support as a strategy to improve general health has been studied with promissory results. However, the concept has not been entirely defined for use as a clinical strategy (Stewart, 1995 and Dennis, 2003) and the effects on health of PSO of PLWHA have not yet been studied.

Based on these conditions, HIV/AIDS is proposed as an especially favourable condition for studying the effects of PSS on biological functioning. The role played by close social networks when facing serious

diseases is crucial (Theorell, 1995) and HIV is no exception (Cohen, 1996). However, being diagnosed as HIV+ has several differences concerned with the social and self-stigma associated with HIV/AIDS (Mak, 2007); another significant issue is the diagnosis disclosure-concealment dilemma resulting in a limited number of people knowing the diagnosis. Since these people are the main option for tension relief and support, they become extremely important to the individual's social network.

Cortés (2003) identified social support as a crucial psychological variable when living with HIV. In a sample of 26 men living with HIV/AIDS a positive correlation was found between PSS and the percentage of CD4+ lymphocytes, while stress and depression were negatively correlated, although in a lower degree than the correlation found between CD4+ and PSS. Based on the available literature, one of the initial hypotheses of this research was to find higher correlations between stress, depression and immune factors; however, the higher correlation was found between PSS and CD4+. Based on this finding it was argued that stress relief and emotional shelter depends on social network availability. Taking into account the reduction of social networks in HIV/AIDS, this factor becomes crucial to a greater extent than in any other health condition. Participants with good PSS had better chances of reducing the effects of stress and depression which are independent of the number of social networks. However, if the perception is of a lack of social support, this reflects lowered likelihood of receiving help to cope with stress or emotional support to deal with depressive mood, and therefore these afflictions were higher. PSS was, therefore, proposed as a mediator of stress and depression in HIV. Nevertheless, the relationship between PSS and immune functioning do not depend on stress or depression (Lutgendorf, 2005).

Based on the given background and considering the cooperative work strategy as an expression of the 'living together cooperatively strategy', this study aims to provide higher understanding of the role played by PSS in HIV/AIDS. To achieve this target, and based on evidence supporting the influence of psychological interventions over physiological functioning in PLWHA (Byrnes, 1998; Donaldson, 2000; Tomakowsky, 2001; Antoni, 2002; McCain, 2003; Antoni, 2005), several sources were studied; psychosocial and immunological longitudinal evaluations were conducted among PLWHA in Chile, an Intervention Programme was piloted with members of a PSO for PLWHA; health professionals and PSOs' representatives were interviewed and a case study was made.

The role of PSS in HIV/AIDS status needs to be investigated deeply, and one of the aims of this research is to extend the understanding in this area. This understanding may lead to a better comprehension of the benefits an approach based on PNI may have in healthcare. This PhD proposes HIV/AIDS as a process that *"occurs as a result of its continuous change in a history of interactions in a medium under a form of epigenesist"* (Maturana, 1988). Therefore, this process can be influenced by environmental modifications. This PhD aims to broaden the understanding of how this process can be modified.

With this purpose, and to achieve a deeper understanding of the impact of cooperative strategies in the process of living with HIV/AIDS, the actors involved in this process, their relationship, approaches and their dynamics of received and PSS were analysed from a trans-cultural perspective.

Chapter Two: Methodology

As a way to facilitate the understanding of the structure of each of the five studies presented, the methodology and the specific methods used in each chapter have been divided:

a) This Chapter discusses the rationale behind the variety of methods and the specific populations included in this research. Here, the aims and research questions, the rationale for choosing the specific population, and the initial contact with participants are presented.
b) The specific methods and design, recruitment and inclusion/exclusion criteria, participants, data collection and data analyses used in each study are described at the beginning of each Chapter.

Social support, anxiety, depression and coping strategies have been associated with physiological benefits in people living with HIV/AIDS (PLWHA). However, the effects of socio-cultural factors on the chosen strategies used by health services and PLWHA themselves to provide healthcare and social support; the impact of specific cooperative strategies to provide social support among peers; and the impact of these strategies on the health status of PLWHA have been underexplored. As stated in the previous Chapter, HIV/AIDS has been described as a complex multidimensional process, where biological, psychological and social variables interact in a relationship which is mostly determined by social discrimination against the individual and lack of understanding. All of these factors should be taken into account to avoid confounding variables when studies are performed. For this reason a holistic approach to understand the proper dimensions of these interactions is necessary. Therefore, and in order to include as many perspectives as possible in the analysis of the

process of living with HIV/AIDS, this research adopts a systemic view which includes psychological, social and clinical approach, plus an analysis of trans-cultural differences. All of this is expressed in the five studies (described below), which aim to answer the following research questions.

2.1. Research questions

Living with HIV/AIDS has been described as an immunological and psycho-social disease; both of these areas affect individuals' general health. This PhD dissertation hypothesises that the stigma and discrimination against PLWHA result in a hostile scenario which in turn increases hopelessness behaviours, which reduce the likelihood of receiving social support. The lack of social support in HIV/AIDS has been proven to be strongly detrimental to health. Cooperative strategies for self-provision of social support, such as PSO, are hypothesised as a crucial activity in facing this scenario and with strong benefits for the general health of PLWHA; however, socio-cultural sensibilities may affect both the provision and perception of social support.

The purposes of this research are:

– To enhance the understanding of the process of living with HIV/AIDS and the role played by social support in the relationship between psychological, socio-cultural and immunological factors;

– To study the cooperative strategies used by each society and PLWHA to (self)provide social support;

– To understand how socio-cultural sensibilities may influence the choices for these strategies; and

– To acquire the necessary understanding to design and implement psychological interventions based on PNI to improve psychological and immune parameters.

With these targets in mind, PLWHA members and non-members of PSO, representatives of PSO of PLWHA and healthcare professionals were studied in England, Romania and Chile. Additionally a case report is presented. Five main research questions:

1. How are PSS, anxiety, depression, coping strategies (approach, avoidance, emotional regulation and reappraisal), CD4+ lymphocytes, viral load level and HAART expressed and correlated in PLWHA from England and Chile?

2. How do socio-cultural sensibilities interact with and influence the approach or/and cooperative strategies; the targets; and the provided and PSS from health professionals and PSO of PLWHA in England, Romania and Chile?

3. How do cooperative strategies to provide social support interact with the health status of PLWHA in England, Chile and Romania?

4. Are there immunological and/or psychological differences relating to the length of membership of PSO of PLWHA?

Will an intervention based on the improvement of PSS and the reduction of anxiety and depression influence immune system functioning of PLWHA?

2.2. Rationale

2.2.1. Rationale for research design

Given that the main target of this research is to enhance the understanding of the multicultural and multidimensional relationship between psycho-social and immunological variables in the process of living with HIV/AIDS, and specifically the relation between those variables and provided and perceived social support (PSS), a diverse range of research methods were chosen. Both the process of living with HIV/AIDS and provided-perceived social support were studied from a general perspective (the study of peer support organisations [PSO] of PLWHA and healthcare teams) to a particular one (PLWHA and a case report). As mentioned, the studies included the perspectives of the most important actors in these processes: PLWHA as individuals, as organisations and as representatives of these organisations; and healthcare team members. Additionally, taking into consideration that these samples themselves are also always only a representation of the population, composed of individual cases (Maslow, 1966) an idiographic view has been included across the four main studies and the case report. An idiographic approach rather than a nomothetic one provides the opportunity to identify and include individual differences in the analysis of the collected data, and to consider the impact these individual differences may have on the relationship between psycho-socio-immune variables.

The focus of this research is the study of each individual's perception of his/her environment. Individuals' perceptions are related to individual characteristics and their specific ways of interpreting their environment and then behaving in it. It is proposed that behaviour is not only related to visible behaviour, but also to physiological functions. For this reason,the

parameters used in this research are focused more on perception (e.g. Questionnaire of Perceived Social Support [CPAS], self-descriptions of anxiety and depression [HADS] and self-evaluation of coping strategies [FDC]) than on a “concrete” measure (e.g. number of networks or individuals; list of symptoms for anxiety or depression). Thus, the most important factor is the individual's interaction within his/her environment, and the quality rather than the quantity of these interactions. Using this approach, it is possible to observe psycho-social behaviour and relate to immune function. An example of this is the Natural Killer (NK) cytotoxicity (how effective the NK cells are in defending the organism), which is a relatively more important factor for health status compared with the total number of NK, an example of quality versus quantity of immune parameters. The extant literature has correlated the quality of NK cells with PSS—specifically, the quality more than the quantity of support (Lutgendorf, 2005). The parallel between psychological and immunological functions needs further research to understand its real importance and significance, as well as possible applications in healthcare. This research included an idiographic approach in order to be able to take into account individual differences within group tendencies. In this way the idiographic approach allows the consideration of individual differences and characteristics and, by comparing those differences with group results, establishes differences that might give novel information about the relationship between psychological and immunological variables in the process of living with HIV/AIDS.

As a way to detect particular differences (the idiographic approach) and to contrast these differences as they play out across diverse cultural contexts, including the study healthcare teams and PSO, research was carried out in three countries (England, Romania and Chile) with similar macro-indicators

in terms of HIV/AIDS but with differences in socio-cultural factors. The cross-cultural approach was used to understand the process behind the specific strategies used by healthcare systems and PSO to deal with HIV/AIDS in each country; the effects of country-specific social characteristics on the approach to PLWHA, if any; the influence of the role played by PLWHA in each country on the way the epidemic is faced; and the effects of these strategies on people's health status. This approach had two targeted populations:

1) Dealing with HIV/AIDS: A cross-cultural view (Chapter Four): Representatives of PSO of PLWHA in England, Chile and Romania were interviewed about their roles, aims and approaches to PLWHA. International organisations and PSO websites in the stated countries were also consulted to complete the collected data and provide contrasting information.

2) Health professionals' view (Chapter Five): Perceptions and viewpoints, approaches and strategies to provide social support and healthcare were studied from health professionals working with PLWHA in England, Chile and Romania.

These two groups (healthcare teams and PSO of PLWHA) were included in order to provide different views of the process of living with HIV/AIDS, beyond the study of PLWHA as subjects themselves. Healthcare team members can give information about how PLWHA are perceived and whether these perceptions have any influence on the treatment of or in the approach to these patients. In the same way, heads of PSO in their political role as representatives of PLWHA and asPLWHA themselves can give a significant and rarely studied view of the process of living with HIV/AIDS beyond the experience of living with the virus. Bearing in mind this

approach, these groups were studied via a qualitative approach, which used open-ended questionnaires exploring how socio-cultural sensibilities interact with and influence the approach or/and cooperative strategies; the targets; the provided and PSS from health professionals and PSO of PLWHA; and how the strategies to provide social support interact with the health statuses of PLWHA in England, Romania and Chile.

Another important area, and one more commonly studied, is the relationship between psychological and immunological variables: psychoneuroimmunology. The interactions between psychological variables and organic functioning have been studied and, as was described in the previous chapter, the link between the two is undeniable. However, in order to use this knowledge in clinical treatment, further research is needed to understand how these interactions work and which mechanisms are behind any correlations between variables and immune function. The literature generally includes results of relatively large samples; however, individual differences can be a key factor for the psycho-immune interaction. Specific personality characteristics, interpretations of environmental situations, types of interactions with social networks or a person's psychological status at a specific moment of his/her life can be a decisive factor in the levels to which psychological, social and immunological variables mutually influence each other. Thus, personality types, coping styles and psychological distress have been associated with faster HIV disease progression. They can affect CD4 cell count, the speed of AIDS progression, the occurrence of opportunistic diseases, and AIDS mortality (Chida, 2009). This research intends to add novel viewpoints to the understanding of this relationship: the perception of both received and self-provided support by and for PLWHA; the effects of socio-cultural characteristics on the provision of this support; how these interactions

affect the health status of PLWHA and how this knowledge can be used in clinical care. In order to have a base for this analysis the interactions between psychological, social and immunological variables were studied using the following approaches:

3) Psycho-immune variables of PLWHA (Chapter Six): This study evaluated and compared psychological and immunological variables in a sample of 25 PLWHA non-members of PSO in Chile. A quasi-experiment in a within-participant design was conducted with the aim of studying the expression of and correlation between psychological and immunological variables in the process of living with HIV/AIDS. Five re-tests points were performed.

4) Psychosocial Intervention Programme - pilot application (Chapter Seven): As stated in the literature review, immunological changes (specifically CD4+ lymphocytes) can be observed daily; however, tendencies in the amount of cells can only be observed within a period of three to six months. Psychological interventions aiming to modify behaviours or psychological status can also take several months. This pilot intends to adapt and adjust the new English version of this programme, learning from the application itself to improve the efficacy of the programme in modifying psychological and immunological variables. However, in a PhD context the time becomes a crucial factor which may strongly influence final results, not because the intervention is not effective, but because—as can be seen in Ohman, 2007—the time from intervention to evaluation is too short to show the real effects of the intervention. Taking this into account, and using a quasi-experimental within-participant design, a pilot application of the Psychological Intervention Programme was tested to acquire experience in the application of the intervention itself, to adapt the intervention to British

participants, to adjust the intervention according its results, to detect weak points in methods or techniques used in the intervention and to optimise time and resources used in the intervention.

The model included a baseline assessment, the Intervention Programme and post intervention assessment, with three months' interval between the evaluations in a control and experimental group. This study also evaluated the psychological and immunological effects of length of membership to a PSO.

A clear example of the possible influence of both psychological and immunological parameters during the Intervention Programme is presented in a case report. In view of the described importance of individuals' characteristics on the psycho-immune interaction, this case is a clear example of how personality characteristics and a given individual's specific approach can be strongly related to the outcome of psychological interventions, specifically resulting in changes in immunological function. This pilot experience and this case report are proposed as a starting point to guide further research in psycho-immune interventions, highlighting specific individual characteristics as key factors for the success of the intervention.

5) Case report (Chapter Eight): A participant in the Intervention Programme who after the intervention had remarkable and sustained long term improvements in both immune and psychological parameters is presented. This case was followed up for two years and seven months (three psychological evaluations) and prospective and retrospective immunological data were collected for a period of three years and six months with intervals of six months (June and December each year).

Ethical approval was granted by the University of Nottingham Research Ethical Committee (REC 1) to carry out the study involving participants living with HIV/AIDS (Appendix E).

2.2.2. Rationale for countries and population

The study of PLWHA, healthcare teams and PSO of PLWHA made possible a more comprehensive understanding of the process of living with HIV/AIDS. In order to approach the meaning of 'cultural difference' in health support, this research studied the differences and similarities among PLWHA in Chile, Romania and England. The research presented analyses possible effects of cultural differences in regard to the process of living with HIV/AIDS, how individuals face the disclosure-concealment dilemma, and what role is played by the PSOs of PLWHA in each society. These countries have generally similar conditions. Such similarities in macro-epidemiology—proportion of population living with the virus, path of acquisition, healthcare benefits and success in epidemic control—provide a scenario that can be studied from several viewpoints, thus achieving a holistic approach, while accounting for the differential psycho-social characteristics of the process of living with HIV/AIDS specific to each country.

Romania and Chile have similar epidemiological factors in terms of number of people diagnosed with HIV/AIDS; 16,877 in Romania (UNAIDS, 2008) and 17,235 in Chile (UNAIDS, 2008b). In the UK the diagnosed cases were 52,083 (UNAIDS 2008c); however, in terms of population, the three countries have similar proportions (per 100,000 inhabitants) of PLWHA (0.104 in Chile, 0.075 in Romania and 0.12 in the UK). All countries are rated as low-level and declared 'under control epidemic' for UNAIDS

(2007). HIV acquisition is mostly via sexual transmission for all three countries, and the most common virus type is HIV-1. The difference is in the subtype B in the UK and Chile and A, B and F in Romania. Additionally, all three countries offer free health care and highly active antiretroviral therapy (HAART), free coverage (not many countries in the world have this status) and use the standard tests for HIV detection (ELISA: Enzyme-linked immunosorbent assay) and monitoring (Flow cytometry for CD4+ lymphocytes and PCR AMPLICOR for HIV viral load). In these countries the epidemic has shown signs of stabilisation; guidelines from UNAIDS for the assessment and monitoring of the epidemic are followed, making comparison possible (UNAIDS, 2009 [online]). Both Chile and Romania ran projects with the financial support of The Global Fund to fight again AIDS, Tuberculosis and Malaria (GFATM) with successful results. These results included the 100% coverage in HAART in Chile and the training of healthcare teams and inclusion of psychologists and social workers to healthcare teams in Romania. In the three countries, there are increasing numbers of new acquisitions of HIV among heterosexuals and women; due to 100% coverage in HAART, a significant rise in life expectancy has occurred. Blood (and its derivatives) and biological tissue (i.e. transplants) are obligatorily tested and HIV tests are compulsory for blood banks. In contrast, many countries in Western Europe have considerably higher levels of epidemic (e.g. Portugal, France and Germany); some Eastern European countries (Hungary, Montenegro and Serbia) have extremely low rates, by comparison. For many countries in Europe (Estonia, Poland, Latvia and Lithuania) and South America (Argentina, Brazil) blood transfusion—mostly by drug users—represents an important pathway of virus acquisition. Parental transmission and drug use are the most important factors in Spain. Some countries (like Italy) are not cooperating with the notification system headed by UNAIDS. Few countries have the

level of macro-epidemic similarities and provide free access to drugs and treatment leading to successfully controlling the epidemic. Based on similarities in the 'macro' level, Chile, England and Romania were chosen for inclusion in this research. Perhaps the most important difference is the comparatively high population of teenagers living with HIV in Romania; this is due to the infection of over 10,000 children in the late 1980's resulting from contaminated blood transfusions and the use of non-sterile instruments. Another difference between these countries is related to the lack of information regarding "risk populations" in Romania; men who have sex with men (MSM), sexual workers (SWs), intravenous drug users (IDU), etc. This indicates differences with Chile and England where these data are available (UNAIDS, 2008). These socio-cultural differences allow a unique opportunity for studying the possible effects of these differences in the healthcare and social support provided for and perceived by PLWHA. Contact with PSO of PLWHA in these three counties allowed the possibility of comparisons regarding the structure and functioning of these organisations, the role played in society and the kinds of support provided to their members.

The target of this research is to study differences in the micro level, specifically as those differences relate to socio-cultural characteristics and social support. The provision of supporting networks for PLWHA and PSO, these networks' effects on the way PLWHA are supported, approached and perceived by society and their effects on general health, if any, are also analysed.

2.3. Participants and settings

Responding to the multidimensional approach that has been defined as necessary to reach a better understanding of the process of living with HIV/AIDS, the participants included across the five studies consisted of the following:

In England; twelve PLWHA from a British PSO, two healthcare team members, a manager of a PSO and the participant described in the case report.
In Chile: twenty-five PLWHA non-members of PSO, three healthcare team members and the director of a Chilean PSO of PLWHA.
In Romania: Four healthcare team members and a director of a Romanian PSO of PLWHA.

2.3.1. Contact with participants

Contact with participants was established via different methods, depending on the availability of modes of contact. Preference was for face-to-face encounters when possible, and phone or email communication when not. The same reasons explain data collection using either email or face-to-face contact. Studies have indicated the effectiveness of email interviews, and have shown several benefits when compared with face-to-face interviews (Hunt & McHale, 2007).

Such benefits are, among others, that email interviews are easy to send; that they are unaffected by distance or time of sending; that completion can be adapted to the timetable of the interviewee; that there is a certain flexibility of time for completion, which allows as much time as the interviewees need for responding; that the interviewee can leave and go

back and review his/her answers, etc. Taking this into account, when face-to-face interviews were performed, a maximum of time for the interviewee was allowed. Of course, the efficacy of e-mail interviews depends on the ability of the participant to express him/herself in writing. However, participants taking part of this study were all either highly qualified health professionals or high-level representatives of national PSO of PLWHA; therefore problems in written expression were not expected.

2.3.1.1. Contact in England

PLWHA were contacted through an East Midlands PSO of PLWHA. Preliminary contact was made via e-mail.

Health professionals were contacted through an East Midlands university hospital. Contact was made via telephone and in person with the head of the department and permission was given to contact other team members.

The **representative of the PSO** of PLWHA (Terrence Higgins Trust [THT]) was contacted through the National Centre in London via telephone and email. Details were referred to the East Midlands regional manager.

The participant who appears in the **Case Report** took part in the Intervention Programme (pilot application), and, therefore, had been contacted through the PSO.

2.3.1.2. Contact in Chile

Contact with **PLWHA** and **healthcare professionals** was made through a university hospital from the Metropolitan Region. Contact was made in person with the head of the specific section.

The **national director of a PSO**; the Assembly of Social Organisations and NGOs with work in HIV/AIDS (ASOSIDA) was contacted by e-mail.

2.3.1.3. Contact in Romania

Contact with **health professionals** was established through a university hospital in the Transylvania region. Data from health professionals were collected during a three-month internship undertaken by the author at the mentioned hospital.

The **national director of a PSO**; the National Union of Organisations of People affected by HIV/AIDS (UNOPA) was contacted by e-mail.

The specific methods, design, sample, settings and instruments were defined by the characteristics of the specific groups studied. As mentioned above, to facilitate the reading of this study these characteristics are described in each following chapter (Chapters Four, Five, Six, Seven and Eight) which present and analyse each one of the five performed studies. All statistic analyses were performed using the SPSS statistical package.

Across these chapters the process of living with HIV/AIDS is studied from a multidimensional and multicultural perspective. This perspective considers individual differences a key factor in the relationship between psychological, social and immunological variables. The intent of this research is to contribute to the clarification of this interaction and to evaluate the impact of PLWHA themselves on the process of living with the virus. This interaction is always perceived by the individual and is always performed in a system in connection with others, conferring upon social interactions and upon the resulting level of support of these interactions a transcendent role in the individual's perception of support and in the process of mutual influence which the individual and his/her environment perform.

The main variable included in this research is PSS; this variable was evaluated using an existing questionnaire showing sensibility to detect correlations between psychological and immunological variables (Cortés, 2003). Chapter Three describes the characteristics of the “Cuestionario de Percepción del Apoyo Social” (CPAS) [Questionnaire of Perceived Social Support] and the validation process that was performed with the British population.

Chapter Three - Validation of the Questionnaire of Perceived Social Support (CPAS)

This chapter includes background on and the validation process of the *Cuestionario: Percepción del Apoyo Social* (CPAS) [Questionnaire of perceived social support]. The CPAS is a self-report questionnaire of perceived social support, developed by the researcher (Cortés, 2003) and is divided into three sections: Section One: demographic data, Section Two: open questions, and Section Three: Likert scale. The validation process was initially conducted with students from England; then data from people living with HIV/AIDS (PLWHA) in England and Chile were used to confirm test validity. The CPAS was translated to English and its theoretical frame was reviewed and updated.

Based on the available theory reviewed in Chapter One, social support is defined as *the perceived level of satisfaction resulting from any social interaction*, giving a fundamental role to concepts such as level of needs, expected support from network and level of satisfaction with the provided support.

3.1. Methods

3.1.1 Instrument: The CPAS background

To assess PSS the CPAS (Cortés, 2003, Appendix F), was used in this PhD. Seven experts in social science were consulted about the questionnaire structure, the variables included and the questions contained. The original questionnaire was divided into three sections with a total of 23 items:

- **Section One** – Demographic data. Three items (a, b and c) related to general individuals' data.

- **Section Two** – Open questions. Nine items (one to nine) related to quantitative indicators of the social networks (e.g. number of networks, number of individuals in these networks) to functioning of these networks (e.g. how often communication occurs, the one to which the interviewee is emotionally closest) and perceived belonging to the closest group (e.g. perceived contribution to the group, level of compromise among the members)
- **Section Three** – Likert scale. Fourteen items (numbers 10 to 23) addressed the quality of support provided by the interviewee's most significant social networks. This is the only scored section of the questionnaire; Sections One and Two work as comparative parameters for the final score given by Section Three

The questionnaire was administered in Chile, obtaining significant correlations with psychological tests and immunological parameters; negative correlations for stress[2] (r: -0,601; p<.05) and depression[3] (r: -0,542; p<.05) and positive correlations for the percentage of CD4+[4] (r: 0,358; p<.05) among PLWH (Cortés, 2003). An adaptation to the British population and a second validation process was carried out as part of this PhD in England (described below).

3.1.2. Participants

The participants comprised 275 students divided into three groups; of these, 185 were female and 90 male. The mean age was 24.21 (SD 2.28 years). The scores reported for each validation stage refers to 'Section Three' of the questionnaire.

[2] Assessed by the Holmes and Rahe self-evaluation Scale
[3] Assessed by the A. Beck Inventory of Depression
[4] Assessed by Flow cytometry.

3.1.3. Statistic analysis

Normality tests were performed in all distributions, Cronbach's α and Guttman split-half were calculated for CPAS administrations, analysis of variance (ANOVA) was performed to study the three student groups, sample size effect (d) was conducted and Pearson's coefficient was used to compare CPAS scores. Based on a common scientific agreement, the analyses considered $p<0.05$ as significant; however, and based on the argument exposed by Dancey (2007) about the arbitrariness of this number, the results were interpreted considering each case and the exact correlation is presented for the analyses. A Factor analysis was used to define the items included in the final test. Data from the pilot application of the Intervention Programme (See Chapter Five) and from the evaluation of PLWHA in Chile (Chapter Four) were used to pilot the new CPAS version; a T-test and Pearson correlations were used to compare students and Chilean PLWHA; and Mann-Whitney and Spearman were used when British PLWHA results were contrasted with those of PLWHA from Chile and with the student results.

3.1.4. Validation process

The validation process included translation into English and retranslation into Spanish; administration points; and modifications after each administration. Three evaluations were carried out with students; the first and the second to adjust the language and, the third, a general administration in the Nottingham University Central Library. A three-stage validation process was carried out.

3.1.4.1. Validation process; stage one – Sample one

The first stage was designed to test the English translation from the original Spanish version of the *"Cuestionario; Percepción del Apoyo Social, (CPAS)"*. An e-version of the questionnaire was sent to 129 students from one department of the studied University, having 17 respondents (Sample One: 13.18% of the population). Several adjustments were carried out to obtain a preliminary English version.

3.1.4.1.1. CPAS modifications

As a result of the administration of the questionnaire to sample one, the following changes were performed to the script in order to improve the quality of the English therein:

- Q4 'Do you think your friends consider it important what happens within your group?' was changed to: ''Do you think your closest friends consider what you do together to be important?
- In Q8 'How important is your contribution to your closest friends?', 'from your point of view' was added at the beginning of the question.
- In Q13 'I feel myself sheltered by my family', the type of shelter was specified: 'I feel myself emotionally sheltered by my family'

3.1.4.2. Validation process; stage two – Sample two

A second evaluation including the changes described was conducted over the same department obtaining 14 replies: sample two (data from respondents from the first evaluation were retained and different participants took part in the second evaluation). Both evaluations obtained similarly high confidence levels (Cronbach's alpha 0.843 and 0.859 and Guttman Split-half coefficient 0.881 and 0.887 respectively). Linguistic and structural adaptations were made to the questionnaire; this process was

supervised by a Spanish language teacher (Ana María Pizarro; School of Modern Languages and Culture, University of Nottingham).

3.1.4.2.1. CPAS modifications

The modifications included the elimination of some items and linguistic improvements:

Eliminated items: two items were eliminated

Q1: 'During the last three months, how many groups or social networks have you taken part in?' refers to the "quantity" of social networks and can state a comparison between the final score which reflects PSS. However, the information this question can give was possible to be obtained from Q2: 'What areas do your social networks or groups belong to?' (Select - with X- all of them), giving both quantitative and qualitative information. For these reasons Q1 was not considered to give new information and therefore was eliminated from the questionnaire. Based on the 31 answers from the two samples, Q17, 'I feel myself represented by my closest group identity' received 51% (16) neutral answers; 72% of those who chose at least one neutral answer included Q17. These answers differ on the tendency of Q10 and Q15 (originally Identification Area) with 19% and 3% respectively of neutral answers. Q17 diverges from the internal validity of the questionnaire and showed low level of discrimination; hence, it was eliminated.

Language modifications: Modifications were mainly related to language accuracy; nevertheless, the key factor was meaning clarification and adjustment to the new theoretical frame. In this way, and to achieve a higher level of reliability in the answers, some extra information was added. In Q2 and Q5 (Which group, of those you belong to, do you feel

closer to?) the response option “Other (Specify) or no one” was separated into two options “Other (Specify)” and “no one”. Additionally the phrase “(Select just one)” was included in Q5. Q7. How often do you usually meet with your closest friends?, was changed to “How often do you usually communicate with your closest friends?” highlighting the hypothesis that PSS is not necessarily the physical presence of people and can be given by non-physical contact (phone calls, internet, etc.) capable of offering informational, emotional, network and companion support (Coursaris, 2009). The answer alternatives for this question were reworded from: Twice a year or less; Once a month or less; Twice or three times a month; Once a week; Twice or more a week; and Every day to a smaller division: Once a week or more; Once a month or less; and Twice a year or less.

In order to make some items more understandable and closer to the original Spanish meaning, some items were reworded or restructured as follows: Q12 was changed from ‘I feel I am listened to enough by my closest friends or partner’ to ‘I feel I can count on my closest friends or partner when I need to be listened to’. Q14 ‘My friends give me good advice for my personal development’ to ‘If I ask for it; my friends can give me good advice for my personal development’. Q15 ‘To be part of a group of friends allows to me know about myself’ was changed to ‘To be part of a group of friends allows me know myself better’. Q19 ‘Most of the time, the solutions of my group, are good’ passed to ‘Most of the time, the solutions to the problems in my group of friends, are useful’. Q21 ‘If it is for my wellbeing, my family will support me’ changed to ‘If it is for my own good, my family will support me’ and Q22 ‘Among my friends we quickly resolve conflict’ was modified to ‘Among my friends conflicts are promptly resolved’. Table 3.1 summarises the modifications to CPAS ‘Section Two’ performed after the first and second implementations.

Table 3.1: Original N and final CPAS version. Section Two.

N in original version	N in latest version	Item	Justification
Q1	Eliminated	During the last three months, how many groups or social networks have you taken part in?	Redundant information
Q2	Q1 Modified	What areas do your social networks or groups belong to? (select –with an "X"- all of them)	Extra Information
Q3	Q2	Do you feel that you contribute to your group of friends?	Not modified
Q4	Q3 Modified	Do you think your closest friends consider the things you do together to be important?	Language improvement
Q5	Q4 Modified	To which group, of those to which you belong, do you feel closest? (Select the closest one)	Language improvement
Q6	Q5	Do you think that you have friends who make an effort –or would do if necessary- in order to maintain your friendship?	Not modified
Q7	Q6 Modified	How often do you usually communicate with your closest friends?	Language improvement
Q8	Q7 Modified	From your point of view, how important is your contribution to the friendship you have with your closest friends?	Extra Information
Q9	Q8	Approximately how many close friends do you have in each of the following groups (if any)? (Put the number in the corresponding category)	Not modified

Section Three is a Likert scale scored from one to five and includes neutral responses; 'neither agree nor disagree', was scored with three points. However, some items have affirmations to which a neutral answer would point to a lack of social support, for instance; a "neither agree nor disagree" response to item 13: "I feel emotionally sheltered by my family" involves deficiencies in family support, and is not a "neutral response". Therefore, lower scores (two points; having the same score that a "disagree" response) on the general test were given to items 11, 12, 13, 18, 20, 21 and 23; this numeration is according the original 23-item version of the questionnaire in Table 3.2.

Finally, and in order to provide an easier and faster self-evaluation of the CPAS, an electronic version was developed. This e-version has a friendly interface, besides automatically providing the final score and a category for each score. In this way, the electronic version offers immediate feedback to anyone who may answer the questionnaire. This option can be easily changed by the questionnaire administrator.

Table 3.2: Original N and final CPAS version. Section Three

N in original version	N in latest version	Item	Justification
Q10	Q9	My closest group of friends has characteristics that provide its own identity.	Not modified
Q11	Q10 Modified	I can freely express my opinion to my partner or group of friends.	Rescaled
Q12	Q11 Modified	I feel I can count on my closest friends or partner when I need to be listened to.	Language improvement Rescaled
Q13	Q12 Modified	I feel emotionally sheltered by my family.	Extra information Rescaled
Q14	Q13 Modified	If I ask for it, my friends can give me good advice for my personal development.	Extra information
Q15	Q14 Modified	To be part of a group of friends allows me know myself better.	Language improvement
Q16	Q15 Modified	I think that my friends give me possibilities to grow	Not modified
Q17	Eliminated	I feel myself represented by my closest group identity.	Low discriminatio n
Q18	Q16 Modified	If I want to talk to somebody, I can turn to a friend or my partner and he/she will listen to me.	Rescaled
Q19	Q17 Modified	Most of the time, the solutions to problems offered by my group of friends are useful.	Language improvement
Q20	Q18 Modified	If I had problems my friend/partner would help me.	Rescaled
Q21	Q19 Modified	If something is for my own good, my family will support me	Language improvement
Q22	Q20 Modified	Among my friends conflicts are promptly resolved.	Language improvement Rescaled
Q23	Q21 Modified	My friends have been able to give me affection when I have needed it.	Rescaled

3.1.4.3. Validation process; stage three – Sample three

The third stage was an evaluation undertaken at the University of Nottingham Central Library, where 244 students answered the latest version of the CPAS questionnaire (21 items); a small number of replies from Plymouth University students (seven) were included in the analysis. Cronbach's alpha was 0.853 and the Guttman Split-half coefficient was 0.836. A total of 275 replies across all 3 administrations were collected, and all had similar results (Table 3.3) showing neither significant differences ($F(2,267) = 1.16$; $p>0.05$) nor important sample size effects, see Appendix G for further details of the performed ANOVA.

Table 3.3: Descriptive statistics for CPAS student administrations

Sample (S)	N	Mean	SD	Size effect (*d*)	Extreme Values
S1	17	56.12	6.46	S1–S2: $d = 0.005$	37 - 63
S2	14	56.21	4.76	S2-S3: $d= 0.331$	47 - 62
S3	244	54.43	5.99	S3-S1: $d= 0.281$	26 – 65
Total	275	54.63	5.97	-	37 – 65

* Test extreme values: 13 – 65

3.1.4.3.1. CPAS: Section Two

Section Two of the CPAS offers several questions related to the number of networks and individuals closely connected with the respondent; gives information about the functioning of the closest group (how often the respondent communicates with this group); and details the perceived level of compromise within the group. These data offer a parameter to be compared with the score given by Section Three, which reflects the perceived quality of received support. In this way, and using the 275 evaluations, low correlations were found between the number of networks to which participants belong and the final score at CPAS (0.2; $p<0.01$); between the closest group (scored higher as fraternal and lower as

institutional) and the final score at CPAS (0.231; $p<0.01$); and the greatest correlation was found between how often participants communicate with their closest network and the final score at CPAS (0.347: $p<0.01$), see appendix H for details. These findings confirm the hypothesis of the lower influence of quantity factors, such as number of social networks, in the quality of received support (Turner-Cobb, 2000; Lutgendorf, 2005; Pressman, 2005).

3.1.4.3.2. CPAS modifications

Of the original 23 items in Sections Two and Three, 16 were retained. The section with the highest rate of items eliminated was Section Two (six items removed: Q1, Q3, Q4, Q6, Q8 and Q9 from the original numeration). One item was eliminated from Section Three (Q17). Section Two contains several items as quantitative indicators of social networks (Questions 1, 4, 6, 8 and 9). Most respondents to Questions 2, 3, 5 and 7 marked the maximum score, lending this question no discriminative power. Therefore, due to this 'ceiling effect', Section Two was not included in the final score. Additionally Q17 in Section Three was eliminated after the second application of the test (31 participants). Based on this, all analyses performed across this thesis, using the CPAS, were carried out based on the new 16-item version.

Eliminated items: Based on item performance across the evaluations, most changes were related directly to the elimination of items:
Q9: 'Approximately how many close friends do you have in each of the following groups, if any?' refers to "quantity" of social networks. This item addressed similar information that Q2 'What areas do your social networks or groups belong to? Select -with "X"- all of them'. Knowing the areas

selected it is possible to know the number of areas (original Q1); additionally, the number of people in each area had a high rate of non-response. For these reasons Q9 was eliminated. Table 3.4 shows the final CPAS structure compared with the original one and the justification for the modification or elimination of each item.

Table 3.4: Relationship between original and final CPAS version

Test Section	Original	Final version	Justification
Section	a	A	Demographic data
One	b	B	Demographic data
	c	C	Demographic data
Section	Q1	Eliminated	Redundant information
Two	Q2	**Q1**	**Retain in final version**
	Q3	Eliminated	Low discrimination
	Q4	Eliminated	Low discrimination
	Q5	**Q2**	**Retain in final version**
	Q6	Eliminated	Low discrimination
	Q7	**Q3**	**Retain in final version**
	Q8	Eliminated	Low discrimination
	Q9	Eliminated	Redundant information
Section	Q10	**Q4**	**Retain in final version**
Three	Q11	**Q5**	**Retain in final version**
	Q12	**Q6**	**Retain in final version**
	Q13	**Q7**	**Retain in final version**
	Q14	**Q8**	**Retain in final version**
	Q15	**Q9**	**Retain in final version**
	Q16	**Q10**	**Retain in final version**
	Q17	Eliminated	Low discrimination
	Q18	**Q11**	**Retain in final version**
	Q19	**Q12**	**Retain in final version**
	Q20	**Q13**	**Retain in final version**
	Q21	**Q14**	**Retain in final version**
	Q22	**Q15**	**Retain in final version**
	Q23	**Q16**	**Retain in final version**

The analysis of the different evaluations showed the limited contribution of questions 3, 4, 6 and 8 to the final result of the test. Practically all of these questions produced a maximum score, indicating low discriminative power; therefore, these items were eliminated. Q2, 5 and 7 were kept as

quantitative factors (number of networks, individuals in each social network and frequency of contact) to be compared with the score given by Section Three.

3.1.4.4. Validation process; factor analysis

As described, the variables included in the CPAS questionnaire are strongly related and mutually influential. For instance, if we understand informational support as the provision of information or advice to assist someone in solving a problem, establishing a feedback interaction, maintaining social identity and integration, increasing confidence and security; and tangible support as the provision of practical and direct help, we may see similar effects and a close relation between these two types of support.

For these reasons and considering previous studies (Mitchell, 1976) a factor analysis with oblique rotation (Promax) was carried out. This rotation allowed the resulting factors to be related among themselves. By contrast, an orthogonal rotation (more commonly used) forces independent factors assuming the factors resulting are not related and can vary in an independent way, making the use of orthogonal rotation theoretically incorrect for perceived social support analysis.

The factor analysis included the 275 administrations of the CPAS (Section Three) and generated three factors (Eigenvalue >1.0) which explain 56.19% of variance (first factor: 36.8%, second factor: 47.47% and third factor a cumulative of 59.19%). Only items loading higher than 0.4 were retained with the factors (Table 3.5). Based on the three resulting factors, described below, and through the analysis of the topics addressed by each question, three new categories or areas emerged.

As shown in Table 3.5, from the factor analysis, factor three had only three items associated with it and one of these was also associated with factor two. To clarify whether there were three or two factors, a new analysis using the same parameters as the first was conducted, but forcing two factors. The two factors only explained 47.47% of the variance (three factors explain 59.19%); three factors were retained, however, more items related to factor three will be included in future evolutions of the CPAS.

Table 3.5: Component Matrix

	Factors		
Item	One	Two	Three
Q11	**0.826**		
Q6	**0.811**		
Q13	**0.795**		
Q8	**0.71**	0.558	
Q16	**0.694**	0.473	
Q5	**0.677**	0.413	
Q12	0.563	**0.728**	
Q10	0.489	**0.708**	
Q15		**0.695**	
Q9		0.681	**0.49**
Q4		**0.481**	
Q7			**0.765**
Q14	0.413		**0.729**

Figure 3.1 shows the scree plot of the factor analysis. This figure, in contrast with the three factors resulting, seems to indicate the presence of only one factor; however, an analysis of the items and their theoretical base may clarify the decision to retain three factors.

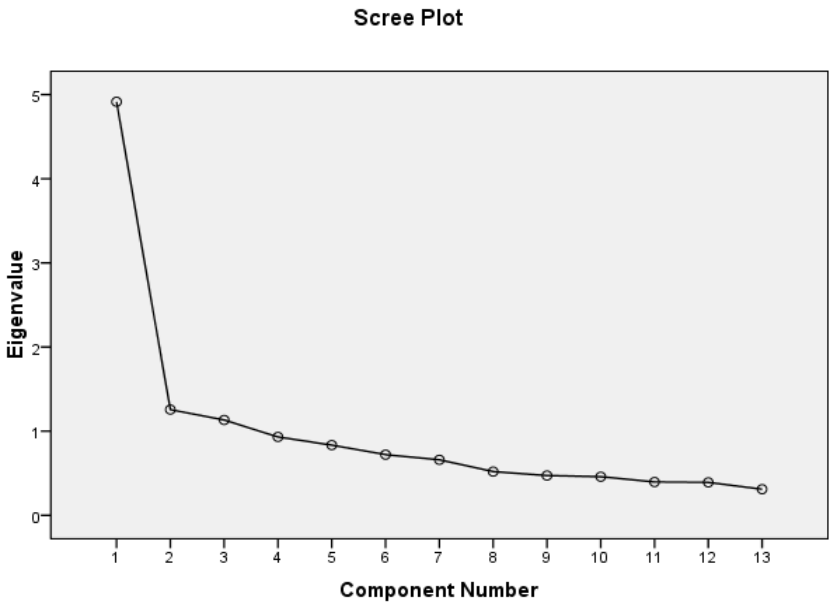


Figure 3.1: Scree plot for CPAS (Section Three)

Table 3.6 summarises the items for factor one:

Table 3.6: Factor Analysis – Factor one: Labelled as Esteem

N	Item
5	I can freely express my opinion to my partner or group of friends.
6	I feel I can count on my closest friends or partner when I need to be listened to.
8	If I ask for it, my friends can give me good advice for my personal development.
11	If I want to talk to somebody, I can turn to a friend/or my partner and he/she will listen to me.
13	If I had problems my friend/partner would help me.
16	My friends have been able to give me affection when I have needed it.

Table 3.7 describes the items for factor two:

Table 3.7: Factor Analysis – Factor two: Labelled as Self-development

N	Item
4	My closest group of friends has characteristics that give it its own identity.
10	I think that my friends give me possibilities for growth.
12	Most of the time, solutions to problems presented by my group of friends are useful.
15	Among my friends conflicts are promptly resolved.

Table 3.8 describe the items for factor three:

Table 3.8: Factor Analysis – Factor three: Labelled as Belonging

N	Item
7	I feel emotionally sheltered by my family.
9	To be part of a group of friends allows me know myself better.
14	If something is for my own good, my family will support me

These three factors belong to different areas of social support:

Esteem: refers to the individual's perception of having been able to express what he/she wanted to and to be listened to in any situation, either if is or not an urgent need, and receiving good advices and affection as feedback. This can be summarised in the idea of feeling esteem from others, boosting one's self-esteem in turn.

Self-development: refers to the individual's identity in terms of group similarities. This seems to be related to the efficiency and efficacy of attempted solutions to problems, which is itself related to the possibilities for development perceived in the group; the perceived opportunities for personal development within the social network.

Belonging: by contrast, this concept refers to a more basic group of needs: the feeling of being emotionally sheltered by the family and the certainty of having familial support if necessary. These needs are related to identity as individual, to self-perception, possibly also to self-value.

These factors refer to three different levels of needs in terms of social support. Basic needs of belonging or even safety are represented by *Belonging*; Acceptance, affection and help from others refers to *Esteem* (for others and self-esteem); and *Self-development* represents the perception of achieving individual growth.

Once the utilisation of three factors had been decided: Q9 ([Table 3.8] Being part of a group of friends allows me know myself better), ranged for factor two (Self-development) and for factor three (belonging), was allocated in factor three. The analysis of the content of the items gives the rationale for this decision:

Self-development items are related to the capacity of networks to help in the solution of problems (Q12 and 15) and the possibilities these social networks offer in terms of development (Q10); all this is associated with group identity (Q4). On the other hand, belonging items are related with a more primary sense of support; emotional shelter (Q7) and family support (Q14). In the same line, Q9 refers to self-awareness and identity, but on an individual level, not in terms of group identity as in Q4. This situates Q9 closer to a primary sense of identity, given by primary bonds, such as family interactions. Based on these theoretical arguments Q9 was retained in factor three, as is considered theoretically closer to the belonging factor.

Quantitative indicators were added to the three described factors. Thereby, three factors of social support and a quantitative referent are evaluated using 16 items.

The final version of the CPAS evaluates self-development, esteem and belonging in social support plus a quantitative indicator. The CPAS includes three demographic items (Section One), three open questions (Section Two) and 13 Lickert items (Section Three). Only Section Three is scored.

3.2. A discussion point

Based on the results of the factor analysis, the three factors can be compared with the four highest levels of the hierarchy of needs, including the safety level (Figure 3.2) identified by Maslow (1943). Maslow described several levels which are arbitrarily hierarchical, but states himself that this is not a rigid hierarchy.

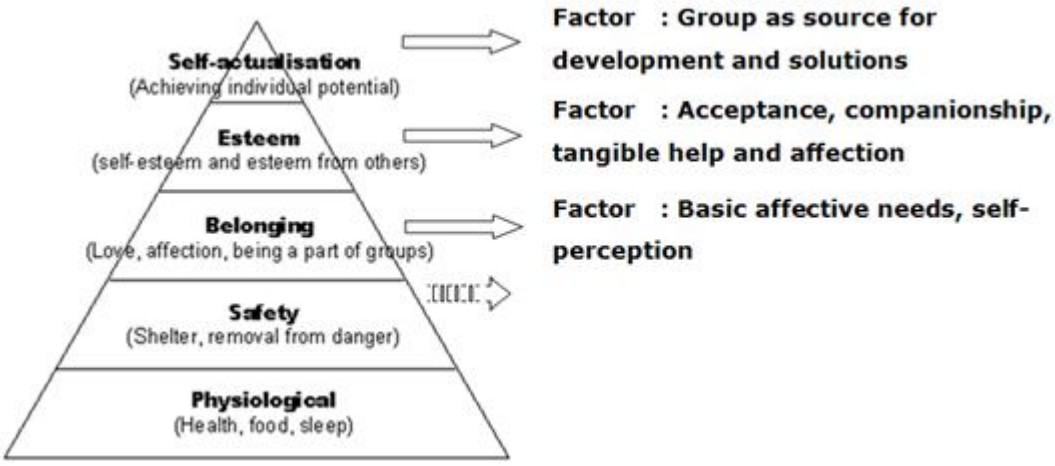


Figure 3.2: Maslow's hierarchy needs and factors in CPAS

Variables and associated items:

The three emerging factors are associated with the top levels of Maslow's Hierarchy of needs and are evaluated by CPAS Section Three. Table 3.9 describes the target of each section of the CPAS questionnaire and evaluates the questions for each area.

Table 3.9: CPAS questionnaire description of content by section

Section	Evaluates	Questions
One	Demographic data	A, B and C
Two	Quantitative indicators of Social Support	1, 2 and 3
Three	Factor Esteem	5, 6, 8, 11, 13 and 16
	Factor Self-development	4, 10, 12 and 15
	Factor Belonging	7, 9 and 14

Maslow (1943) described the hierarchy of needs as follows:

- The first described level was that of *physiological needs* tending to maintain homeostasis in the organism, described as the most pre-potent of all needs, e.g. hunger, health and sleep.

- The second level is *safety needs*, described as capable of dominating the organism at the same level as physiological needs. Maslow even describes the whole organism as a "safety-seeking mechanism" capable to use all its

skills for the seeking of safety, sometimes leaving even physiological needs in second place. This statement gives a theoretical reaffirmation of the significance of cooperative strategies for the self-provision of social support used by PSO of PLWHA as a safety-seeking mechanism. Maslow described groups which are successful in making their members feel safe from threats as "*peaceful, smoothly run, and good societies*". Therefore, those groups experiencing an unsafe environment—for instance one in which they or their members are discriminated against as stigmatised minorities, such as PLWHA—may not be satisfied by general society in their safety needs. However, Maslow also described such negative environments as potent mobilisers of the organism's resources, which may explain the appearance of PSO and the leaders behind these organisations.

- The third level is that of *love needs,* described as affection and belongingness needs, which are the organism's seeking for a basic, affective, bidirectional interaction. *Safety* and *love needs* were linked with the *belonging* factor resulting from the CPAS analysis and referring to the feeling of being emotionally sheltered, which is related to one's identity as individual, to self-perception, and to self-value.

- The fourth level is that of *esteem needs,* which is related to self-respect and self-esteem, but also to respect, esteem and evaluation of and form others. In other words, this represents the perception of an individual, highly related with group perception, appreciation and recognition. It is possible, therefore, to see a strong connection between *love needs* and *esteem needs*; both are related to acceptance and affection; nevertheless, the first is more linked to individual affections and the second with group affections and acceptance. *Esteem needs* was linked to the *esteem* factor of the CPAS, which refers to the individual's perception of being accepted

by the group and feeling esteem from others, boosting his or her own self-esteem in turn.

- The last level is the *need for self-actualisation*, described as the possibility of the highest creativity based on the satisfaction of all the previous needs and as the need to maintain growth. Maslow, however, sets some exceptions such as individuals who develop and use the greater part of their skills under highly adverse environments. This need was linked to the *Self-development* factor of the CPAS, referring to the individual's identity related to the efficiency and efficacy of attempted solutions to problems and possibilities for general and personal development perceived in the group and within the social network.

These results may indicate the capacity of the CPAS for measuring Maslow's needs. It is not intended to be the final instrument to such purpose; however, it may represent the initial structure of a questionnaire capable of being a reliable measure of actualisation. Several attempts to measure Maslow's hierarchy needs were described during the 1970s and 1980s: Payne (1970) Roberts (1971), Herman & Hulin (1973), Waters & Roach (1973) and Webber & Hadd (1974); however, according to Mitchell (1976) all these attempts have a common problem in that all of them performed factor analysis with orthogonal rotation which assume an independence within the factors, independence that by the theoretical definition of Maslow's hierarchy of needs cannot be assumed; in fact, these levels were defined by Maslow (1943) as superimposed with each other. Bentz (1984) developed two measures addressed to women's need of fulfilment. No further attempts to measure Maslow's hierarchy needs were found in the literature, nor in final instruments. The CPAS offers an opportunity to evaluate the level of self-actualisation in relationship with

PSS in the context of PNI. This involves a different approach to the hierarchy of needs and the impact those may have on health status. Further research could pursue this in depth.

3.3. Final version

A final CPAS 16-item version was developed. This questionnaire is presented in two versions; traditional and electronic self-tabulated. This new English version, besides being a shorter test, offers a validated instrument for the assessment of PSS with a new theoretical base on Maslow's hierarchy needs. The traditional format for the CPAS 16-items is available in Appendix I.

3.3.2. Structure of the final questionnaire

In summary, this questionnaire is based on the *receiver's perception* category of social support (Procidano and Heller, 1983). The main constructs evaluated are those identified by Cohen (1992): *supportive networks, supportive behaviours* and *emotional support*. The specific areas evaluated include *social networks* and *supportive behaviours* but the evaluation is focused on *emotional support*. This is based on the significance of *individual needs of support* and *satisfaction levels* (Dunkel-Schetter and Bennet, 1990). This theoretical structure takes as foundational four specific variables commonly described in social support: *Emotional support, tangible support, informational support and comparison support* (Bogossian, 2007). The CPAS evaluates positively or negatively each one of these variables; additionally, includes a quantitative indicator of social networks (Section Two).

Section One of the CPAS includes three items: a) ID, b) Age and c) Sex. This section is not scored. Section Two works as a quantitative indicator of social networks; each item can be compared with the final score (Section Three). This section is not scored.

3.4. Conclusions

A 16-item English version of the CPAS has been validated for the British population. Three factors have emerged for analysis and more items will be developed. In terms of its administration to PLWHA, generally lower scores of PSS were founded over the assessed participants when compared to students' scores in England. Anxiety and depression (HADS) were negatively correlated with PSS. This indicates the relationship between depressive or anxious symptoms with perceived support. Considering the reviewed literature, these results are in the expected direction, due to the rupture in social networks usually reported for PLWHA and the higher levels of anxiety and depression commonly reported. Once more, this is interpreted as an indicator of the discriminative power of the CPAS and as an example of validity and reliability.

This validation has provided significant information related to the administration and performance of the CPAS questionnaire. Further analysis and interpretations of the different evaluations in Chile and in England can be found in Chapter Four, Chapter Seven and Chapter Nine. Although the CPAS has been addressed to PLWHA, it can be used with different populations. This questionnaire intends to be a contribution to the study of PSS.

Chapter Four: Dealing with HIV/AIDS: A cross-cultural view

In order to answer the research questions, different approaches were used to collect data regarding HIV/AIDS in its psychological, social, cross-cultural and immunological dimensions. Five studies of three main groups: people living with HIV/AIDS (PLWHA), health professionals, and peer support organisations (PSOs) of PLWHA were performed, obtaining a holistic view and a diverse variety of data. Additionally, a pilot application of the Psychosocial Intervention Programme and a case study are described in Chapters Seven and Eight, respectively. This is the first of five chapters related to the results and analysis of the different studies performed.

In this Chapter the approach of PSO to PLWHA is analysed by interviewing an experienced, upper-level representative of PSOs in each of the three countries: UK, Romania and Chile. The purpose of this was to understand the ways in which social support is self-provided to PLWHA by PSOs of PLWHA and how this impacts on PLWHA and society in general. This chapter analyses the influence of socio-cultural characteristics on PLWHA's decision to start PSOs; the roles and targets of PSOs; their structures; their reasons for existing as organisations; and their relationship with society in general. The influence of PSOs on people's perceptions about HIV/AIDS; on country-specific strategies for dealing with HIV/AIDS; and how this process influences both provided and perceived social support for HIV/AIDS, are also analysed. Finally, the effectiveness of peer support strategy in healthcare for PLWHA and how this strategy might be a key factor for an integrative healthcare strategy in HIV/AIDS is discussed.

4.1. Living with HIV/AIDS; Background

As a starting point and prior to reporting of the results of this study, the general background of HIV/AIDS in each country and the reasons underlying the founding of each organisation are described.

As proposed in Chapter One, the 'living together strategy' is proposed as our current strategy by which we provide ourselves with social support. This strategy becomes more visible in situations where social support and membership to social groups are affected. Living with HIV has proved to be far more than a question of biological health due to the high levels of stigma and discrimination against PLWHA (Spirig, 1998; Liamputtong, 2009). As a strategy for combating an environment of general discrimination, PLWHA have established PSOs in almost every country across the globe. Diverse approaches, structures and strategies to achieve their targets can be observed; however, working cooperatively to reduce social stigma and discrimination against PLWHA is the common denominator, as reaffirmed by the representatives of the National Organisations of PLWHA in England, Romania and Chile.

The Terrence Higgins Trust (THT) was named in honour of one of the first person dead by AIDS in the UK. His friends and family started the organisation in response to the stigma and discrimination around HIV/AIDS in the general population and health services.

In Romania, *UNOPA was formed in order to meet the needs of the PLWHA living in Romania, especially those of the YPLWHA [Young PLWHA]* (National Director of UNOPA, Romania). Between 1986 and 1991 approximately 10,000 children were infected with HIV by exposure to

contaminated needles and micro-transfusion of unscreened blood which occurred in hospitals and orphanages. Stigma and discrimination against PLWHA have affected access to education, medical care, governmental services, and employment. (Human Rights Watch [HRW], 2006).

In Chile, ASOSIDA was created as a reaction to discriminative scenarios similar to those described in the UK and Romania. The organisation was started in the mid-1980s as an answer to the appearance of the first HIV/AIDS cases in the country, which mainly affected gay men. At that time Chile was under a fascist dictatorship, which was a primary factor in the initial lack of response from the state, coupled with cultural difficulties which underpinned discrimination. However, despite a momentous change in Chilean culture after regaining democracy, PLWHA still suffer from homophobia and stigma.

PLWHA organisations offer a wide range of services: psychosocial support, up-to-date HIV/AIDS related information, legal advocacy, and primary and secondary prevention strategies for the population in general. However, perhaps the most important service provided by these groups is the use of peer support as primary strategy. An individual living with HIV/AIDS who approaches one of these institutions may perceive that he/she is being greeted with a high level of understanding, acceptance and personal validation by true peers living with the same condition, rather by than medical institutions. This takes on additional relevance for recently diagnosed people seeking support and understanding of their situation, transforming PSO into natural sources of *comparison support* as stated by Bogossian (2007) and described in Chapter One. This PhD proposes the peer support strategy used by PSO of PLWHA as being capable of positively influencing the health status of members of these groups.

4.2. Participants and methods

4.2.1. Participants

PLWHA organisations have emerged worldwide and have been described as offering emotional support, advocacy and guidance to their members (UNAIDS, 2008). In this context, the most important PSO in each of the studied countries (UK, Romania and Chile) was included in this research. Open-ended questionnaires sent via e-mail were performed, due to the restricted agenda of the national directors of the Assembly of social organisations and NGOs with work in HIV/AIDS (ASOSIDA) and the National Union of Organisations of People affected by HIV/AIDS (UNOPA). However, in England, contact was referred from the Terrence Higgins Trust's (THT) central administration in London to the regional office for the East Midlands Centre, who offered an in-person meeting. Therefore in-person data collection was conducted in this case. In this way, single high-level representatives with extensive experience and central roles in the representative PSO of PLWHA in each country were contacted. These comprised the Manager for Nottingham of THT in England; the National Director of ASOSIDA in Chile; and the National Director of UNOPA in Romania. The three interviewees were coded as shown in Table 4.1.

Table 4.1: Code for representatives of PLWHA organisations

Position		Country		Organisation	Sex	
National Director	**ND**	Chile	**Ch**	**ASOSIDA**	Masculine	**M**
		Romania	**Ro**	**UNOPA**	Masculine	**M**
City Manager	**CM**	United Kingdom	**UK**	**THT**	Masculine	**M**

E.g. ND/Ro/UNOPA/M: is the National Director in Romania of UNOPA and is a Man

The disparity between the representatives (ND in Romania and Chile, and CM in England) may restrict the information in England to a regional level

while data from Chile and Romania were from a national view. However, this difference allowed a wider viewpoint from two crucial perspectives: the top and the middle level of the institutional hierarchy, giving practical examples of the strategies described by the heads of the organisations.

Sample: Three high-level representatives of PSO of PLWHA in Romania, Chile and England. The main national PSOs of PLWHA in these countries were included: the Terrence Higgins Trust (THT) in the UK, the Assembly of social organisations and NGOs working in HIV/AIDS (ASOSIDA[5] from Spanish acronym) in Chile and the National Union of Organisations of People affected by HIV/AIDS (UNOPA[6], from Romanian acronym) in Romania. The interviewees qualified as experts in PSOs of PLWHA, in the services these organisations provide, and in the scenarios PLWHA have to face in each country.

Table 4.2: Inclusion – exclusion criteria for representatives of PSO

Inclusion	Exclusion
a) Representatives of national PLWHA national organisations b) Fluent in English – British participants c) Fluent in English – Romanian participants d) Fluent in Spanish – Chilean participants	a) Members or representatives of local PLWHA organisations b) Do not speak English or Spanish

Informed consent: Two ways of obtaining informed consent were used: firstly, participants gave written consent to take part in the study, after being provided with oral and written information about the research and before any questions were answered (THT representative). Secondly, participants provided electronic consent (ASOSIDA and UNOPA representatives). The consent information was sent by email along with the

[5] Asamblea de Organizaciones Sociales con trabajo en VIH/SIDA
[6] Uniunea Naţională a Organizaţiilor Persoanelor Afectate de HIV/SIDA

information sheet and the open-ended questionnaire. Participants were encouraged to ask any questions or express doubts regarding to the project before starting answering. Consent was assumed to be implied where participants completed the open-ended questionnaires and emailed them back to the researcher. This assumption was made explicit in the emailed information.

4.2.2. Procedure

The procedure for data collection was performed by e-mail or in person depending on the possibility for such implementation.

In Chile and in Romania, due to distance and representatives' schedules, the open-ended questionnaire was implemented over e-mail. Participants had a designated space were they could write their responses and some questions had several options for further questions depending on previous responses. **UNOPA** was created by the parents of children infected with HIV and has 23 offices around Romania. The open-ended questionnaire was sent to the National Director of UNOPA (ND/Ro/UNOPA/M). Initial contact was performed in Romanian. However, data collection was conducted in English. **ASOSIDA** is a coalition of 55 organisations in Chile, and is one of the most important civil services for PLWHA in the country. The open-ended questionnaire was sent via email to the National Director of ASOSIDA (ND/Ch/ASOSIDA/M). The contact and open-ended questionnaire were performed in Spanish. In England, data collection was performed in person and detailed notes were taken. **THT** is the largest HIV and sexual health charity in the UK, located in 27 centres in England, Scotland and Wales. The open-ended questionnaire was administrated to the Nottingham City Manager (CM/UK/THT/M) in English.

Data collection was conducted in February 2009 in Romania, April 2009 in Chile and June 2009 in England. Additionally, and as a way to complement this information, reports from national and international organisations working in HIV/AIDS were consulted. Among these were UNAIDS; the Global Fund to fight against AIDS, tuberculosis and malaria (GFATM); Human Rights Watch; the Center for Disease Control and Prevention (CDC); the Food and Drug Administration (FDA); and the studied PSOs' websites.

4.3. Materials and instruments

Two main targets were defined to be analysed using data from the representatives of the PSOs.

- To understand the interviewees' perceptions about the role played by their organisations for their members and society.
- To understand the interviewees' perceptions about how their organisations conceive of social support and how this support is provided to members of those organisations.

Based on these targets six topics were defined for exploration:

- Each organisation's starting point: The history and the context that necessitated its creation.
- Each organisation's roles and aims: the reason each organisation exists and the needs each organisation fulfils.
- The greatest achievements of each organisation: its most important achievements and how this helped PLWHA and society
- Group structure: How each group is organised and governed

- Programme and activities for members and society: each group's approach to its members and to society in general.
- Main difficulties for each organisation and for PLWHA: How does the organisation deal with difficulties and how does it support PLWHA to do so.

Based on the described topics an open-ended questionnaire with 14 items and eight sub-items was developed.

4.3.1. Open-ended questionnaire structure

The same open-ended questionnaire was used with each representative and administrated via email or in-person. Every open-ended questionnaire included the following statement:

STATEMENT: This open-ended questionnaire is part of a PhD research programme carried out at The University of Nottingham, England. The information provided will be seen only by the researcher and his supervisors. **Permission is requested** to interviewee **to use quotations from the questionnaire** in the data analysis of the final Doctoral Thesis. All personal information is subject to the University of Nottingham confidentiality guidelines and laws[7].

[7] Contact and related information was available in the Information Sheet provided to each participant.

4.3.2. Open-ended questionnaire script

1. Why was the organisation formed?
2. What were the initial organisational aims?
    a. Are they the same now?
    b. If they have changed, what are they now?
    c. Why have they changed? (if relevant)
3. From your point of view, what is the role that the Organisation plays as a social supporter of PLWHA?
4. What role does the Organisation play in society in terms of promoting HIV/AIDS understanding, if any?
5. How does the Organisation provide social support to its members?
6. How does the Organisation intend to achieve its described aims? (Question two)
7. What have been the organisation's greatest achievements?
8. How is the Organisation hierarchy and structure?
9. Are there any strategic divisions or areas within the group? What are they? (i.e. psychology, legal advocacy, new members support, etc.).
10. If yes, why was this structure established?
11. In broad terms, what programmes or activities does the Organisation undertake for its members?
12. Are there activities, coordinated by the Organisation, directed at interaction with people not living with HIV? What are these activities, and what are their targets?
13. What are the most common problems that the Organisation has to deal with?
    a. How does the Organisation deal with them?
    b. How has the Organisation advanced toward the solution of the described situation?
    c. What problems, if any, have been solved?
14. Which are the most common problems that PLWHA have to deal with in British society?
    a. How does the Organisation help its members to deal with these problems?
    b. **If these problems are related with discrimination:** Is the Organisation doing something to alleviate negative social perceptions or stigma surrounding PLWHA?

4.3.3. Data analysis

The analysis performed began with the transcription of notes into a digital media. In the case of Chile, the data were first translated to English; in Romania the interview was performed in English. Comparisons were drawn in order to identify common themes and to explore similarities and differences in the approach to PLWHA and how the organisations offer social support in the UK, Romania and Chile. Responses to the open-ended questionnaires were grouped into themes and a *thematic analysis* was performed. These data complemented the information obtained from PLWHA, health professionals and international organisations. In this way, a country comparison was undertaken including both performed studies.

4.4. Results - Main themes and cross-cultural perspectives

This section has been divided into two parts. The first part deals with cultural differences and similarities, consisting of an analysis of key themes: main problems for PSOs; main problems for PLWHA; strategies for dealing with PSOs' problems; and strategies for dealing with PLWHA problems. These themes are analysed, then compared to the general aims and roles of the organisations. The second part of this section analyses the interaction of the PSOs with society in general, the organisations' greatest achievements and how support offered for PLWHA is influenced by socio-cultural characteristics.

4.4.1. Cultural differences and similarities

In order to gain a deeper understanding of the problems PLWHA must cope with and the support offered by PSOs, representatives were asked about

organisations' and individuals' main issues related to HIV/AIDS, the key themes were as noted below.

4.4.1.1. Problems for organisations

Problems PSOs faced included economic problems, lack of compromise with prevention, homophobia, lack of sexual education and inefficiency of medical systems. These problems are interpreted by PSO representatives as the result of stigma and discrimination against PLWHA.

In Chile the problems described were:
"*…the lack of economic resources and a lack of governmental compromise to the development of preventive work. …homophobia within state institutions and a lack of support from health public services to GLBTI* [Gay, Lesbian, Bisexual, Transgender, Transsexual and Intersex] *population needs. …a strong resistance to sexual education and use of condoms by the Catholic Church*".
ND/Ch/ASOSIDA/M.

In Romania the main problem described was:
"The inefficiency of the medical system that leads to a lack of ARV treatment in the hospitals, and therefore leads to treatment interruptions for the PLWHA".
ND/Ro/UNOPA/M.

In England the problem described responds to an absolutely different level of concern:
"Convincing other organisations that we are not here to "steal" clients".
CM/UK/THT/M.

These responses establish a difference related to the status of national network that Chilean and Romanian organisations have; in England there are different organisations targeting the same clients also present at a national level, but without a strong cooperative presence to each other. Therefore, this may lead to misunderstanding or overlaps such as the one described by the THT manager. This perception of "rival" organisations is not possible in Romania since UNOPA is the only organisation for PLWHA. In Chile, the problem was solved by national coordination and cooperative work in a nationally organised network.

The representatives' responses are a clear example of the differences in priorities and perspectives that the three interviewees have, presumably due to their different roles within their respective organisations. These differences provided insight into the everyday difficulties of the organisations which, as can be seen, may be not related to difficulties at the national level, but may still seriously affect organisational targets, and strategies to achieve these aims.

4.4.1.2. Problems for PLWHA

These responses coincide with the literature and with healthcare professionals' views (Chapter Five); discrimination, social exclusion, rejection and isolation are the common denominators of the unfriendly scenario that necessitated the creation of PSOs.

In Chile the most common problems for PLWHA were:

"*…related to discrimination and social exclusion. …there are still discriminatory behaviours and strong rejection in society".*

ND/Ch/ASOSIDA/M.

In Romania the responses were similar:

"Romanian society's mentality, their lack of information about the HIV/AIDS problem, their reluctance to know more about it and the situation… [and] *the discrimination they still show to PLWHA".*

ND/Ro/UNOPA/M.

And again in England:

"With the clients, social stigma and isolation".

CM/UK/THT/M.

This aggressive contextualisation is the basis for considering HIV/AIDS as a 'special' condition that involves a process of acceptance that leads to being able to live with the virus. Social stigma and isolation do not only effect PLWHA psychosocially, but immunologically as well. The neuro-immuno-endocrine pathway allows stressful situations, like living with HIV and the stigma and social isolation associated with living with HIV, to impact the immune system. This directly affects the individual's health status. Interestingly, one important factor which causes changes in the autonomic endocrine and immune system is a threat to social status (Kemeny, 2009). This is also one of the most common side-effects described for PLWHA (Simbayi, 2007, De Castro-Silva, 2008; Genberg, 2009; Liamputtong, 2009; Vyavaharkar, 2010). It is in this process that the 'living together' strategy becomes crucial as a base for the positive effects of peer groups and their cooperative work towards defeating people's '*reluctance to know*', prejudice and improving the health of PLWHA.

4.4.1.3. Strategies addressing organisational problems

Cooperative work with other institutions or within each PSO was situated as one strategy for managing institutional problems.

In England, as a way to improve its image as a "friendly institution" working towards a goal it holds in common with other organisations, THT has been trying to promote:

"…open work with them [other organisations of PLWHA]*;* [establishing that] *the more services the better for the people. We are their "best friend", and most of the* other organisations *perceived us as help.*

CM/UK/THT/M.

In Chile the strategy is to be stronger as a network with national presence, and in this way to become more visible to the authorities.

"The work is in networks and national organisations to take on topics of national concern. Moreover, awareness actions are taken towards public authorities. Others key factors are public denunciation and media communication".

ND/Ch/ASOSIDA/M.

The Romanian strategy partly coincides with the Chilean approach:

"UNOPA has tried to foresee these problems [lack of antiretrovirals] *and has striven to solve them before they take on national proportions. For this purpose the UNOPA representatives repeatedly met with the responsible authorities and urged them to take action for solving the problems immediately".*

ND/Ro/UNOPA/M.

Cooperative work within organisations is used as detailed above in Chile and in England; in Romania practically every organisation of PLWHA is part of UNOPA as a national network, and therefore this network acts as one voice in support of PLWHA. In England, networking seems not to be used as strategy on a national level. Nevertheless, the need for cooperative work with other PSOs emerges in the regional level as a key factor in making the work of the organisation possible. This is the main difference between the three countries in terms of strategies for coping with organisational problems. Additionally, representatives from all three countries mentioned lobbying campaigns as one of their organisational focuses.

4.4.1.4. Strategies to deal with PLWHA problems

Interviewees in the three countries agree that "*information*" is the key factor in helping PLWHA with discrimination.

"[The organisation] *carries out actions of social awareness, promotes non-discrimination values by using educational campaigns, and performs training for PLWHA with the purpose of strengthening and empowering them, especially regarding their rights.* [The organisation] *offers legal advocacy and social support, and coordinates with other organisations and networks to improve the impact of the performed actions. AIDS law is issued using organisational websites".*
ND/Ch/ASOSIDA/M.

"UNOPA helps its members by legal and official representation in relations with the Romanian authorities, with the Ministry of Health and the Ministry of Work, Family and Equality of Chances, by court representations".
ND/Ro/UNOPA/M.

"With one-to-one support, by empowering them, by giving them information; HIV is not who you are, is what you got. This can be accomplished by education, avoiding secrecy; that is why there is stigma: so much lack of knowledge".
CM/UK/THT/M.

In this way, differences are established in the role given by the organisations to the PLWHA. In England and Chile, the main focus is using the information to 'strengthen and empower' people. A precise example of this is the use of peer support, as cited by the THT manager: "*HIV is not who you are, is what you got.*" In Chile, ASOSIDA conducts massive awareness campaigns and training courses for PLWHA. Behind these strategies lies the belief that people can manage their own problems and the way to help them is by making information available. The impact of the peer support strategy has proven an important factor in improving HIV understanding; there were significant positive differences in HIV knowledge and safer sex behaviour among students involved in peer group education when compared with traditional education programmes (Mahat, 2008)In Romania, the focus appears to be on representing people rather than on empowerment strategies; informing communication media about discriminative situations and following legal processes on behalf of PLWHA victims of discrimination. This "paternalism" is coherent with UNOPA's origins -parents of children living with HIV/AIDS.

4.4.1.5. Aims and strategies

All three countries coincide in their main organisational target: "*Defend the rights of PLWHA*". The use of different strategies to reach this similar target speaks about the influence of cultural differences on PLWHA organisations and on their social processes. In England and Chile the strategy used to defend individuals' rights can be summarised as "*empowering PLWHA to improve quality of life and health*". On the other hand, the strategy for Romania has been for the organisation to be "*the national voice to represent PLWHA*".

In Romania factors such as poverty, lack of information and prejudice from a conservative society highlight the need for the organisation to act as a voice and guard of PLWHA's rights. The mission of UNOPA has been established as:

"*…based on advocacy for the promotion and defence of the rights of people infected and affected by HIV/AIDS in Romania*".
[UNOPA website]

And the strategy used to defend and support PLWHA is:
"*…providing social support to members by ensuring the right to social protection adequate for the needs of the people infected/affected by HIV/AIDS and to adapted psycho-social support; the right to non-discrimination and social inclusion;* [and] *the right to education and socio-professional integration.*
ND/Ro/UNOPA/M.

Legal advocacy and representation are offered to those who want to prosecute for PLWHA rights violations. In this way, the organisation

"…is a national-level voice for transmitting to the communities and the entire society correct information about HIV/AIDS and about the real situation of PLWHA and their families.
ND/Ro/UNOPA/M.

In England, the intention of humanising HIV/AIDS by naming the institution in honour of one of the first people in the UK to die of AIDS is made explicit in the institutional mission statement:

"*Empower everyone living with HIV in the UK to maximise their health and wellbeing by working to ensure the best possible HIV treatment and support services*".
[THT website]

This perspective has at its base the need for empowerment to bring about changes in stigma and discrimination, highlighting individuals' inherent skills in defending themselves:

"*The idea is to support people until they can support themselves; peer support has been the base of this strategy.* [We] *give talks about sexual education in schools (from 12 years old) and at universities*".
CM/UK/THT/M.

The population living with HIV/AIDS in the UK are in general homosexual men. However, the number of women and heterosexuals has grown in the past years. The number of people seeking asylum, most of them adults

who acquired the virus via sexual relations, has also grown. The role of THT is empowering PLWHA to defend themselves against a discriminative society. However, discrimination against homosexuals and PLWHA makes this work difficult and this discrimination often comes also from health professionals.

"With the clients, [the main problems] *are social stigma and isolation. Discrimination is the main problem for PLWHA* [and in terms of homosexuality?] *yes, huge too, that needs lot of work in society.*
CM/UK/THT/M.

In Chile the strategy is similar to the one used in the UK, focusing on empowering people rather than only defending their rights. The mission statement of ASOSIDA puts it thus:

"*Doomed to reduce the epidemic's social impact in Chile through collective reflection, resource mobilisation and the development of proposals that deepen and expand participation of civil society*"
[ASOSIDA website].

Accordingly, the organisational aim is:
"*Mainly the organisation was initiated to educate the gay population about the risk of AIDS and to undertake a massive VIH/AIDS prevention…*"
ND/Ch/ASOSIDA/M.

Despite yearly campaigns, according the national director of ASOSIDA, only in recent years have the messages been clear and direct, not influenced by relatively small conservative sectors within Chilean society, usually linked to conservative political parties and the Catholic Church. To deal with this

opposition, active and public campaigns like "Condonito" (a giant smiling yellow condom that visits beaches handing out condoms and giving sexual education, talks and leaflets) are emblematic of how ASOSIDA tries to achieve its goal of generating debate about HIV/AIDS across society.

"The Organisation since its origins has contributed to the debate related to universal access to healthcare and social inclusion of PLWHA.
…Communication is one of the main strategies to generate debate and social awareness…".
ND/Ch/ASOSIDA/M.

4.4.2. PSOs in society, achievements and PSS

This section briefly describes the main services offered by the PSOs in the three countries, analyses the strategies behind their workings, and looks at how socio-cultural aspects influenced the choice of their specific approaches to people living/affected by HIV/AIDS. HIV/AIDS affects the entire society; therefore, the PSOs, despite some differences, all address society as a whole.

The PSOs offer the following services:
Romania: Until 2006, eight projects were conducted with the support of a Global Fund project awarded to the country (Global Fund, 2008). Current programmes still in progress involve legal consultancy for PLWHA and social diffusion, with activities such as:

"Conferences, seminars and work meetings; public campaigns, protests, open letters, solidarity appeals, manifesto, press releases or conferences;

exhibitions and shows; publications (monitoring reports, "Pozitiv" magazine); and court representation".

ND/Ro/UNOPA/M.

UK: A large range of services are provided. However, these services change depending on each centre. Among those offered are a helpline, youth services, counselling and group support, information and advice on managing your own health, practical support services and, testing for HIV and other STIs (THT website). Additionally:

"Pride parade once a year, Fresh fair 10 or 12 times a year, and distribution of leaflets and condoms packs".

CM/UK/THT/M.

Chile: a large variety of services are also provided, such as:

"…psychological and social attention, programme for parents and siblings of gays, lesbians or transsexuals, informative phone-line, courses and training programmes, talking groups for PLWHA, activities for recreation and to deal with burnout, legal consultancy, cultural activities, film seasons, forums and debate, exhibitions, Pride parade, literary seasons, photography competition, etc.".

ND/Ch/ASOSIDA/M.

The activities undertaken by UNOPA reflect the active role of the organisation in being the voice of PLWHA; in England the emphasis is given to the extensive variety of offered services and in Chile to individuals' participation.

4.4.2.1. Strategies for interacting with the society

The described activities reflect the strategies behind all these institutions and make clear the organisations' intention of providing support and education to their members and society as a whole. These strategies are also intended to reduce discrimination against and stigmatisation of PLWHA by increasing awareness and reducing myths surrounding HIV/AIDS. The National Director of ASOSIDA is clear in this regard and maintains:

"*…peoples' serologic state makes no different; as far as the activities and programmes go, our intention is the inclusion of people, regardless of whether or not they are living with HIV/AIDS*".
ND/Ch/ASOSIDA/M.

This reflects the emphasis given in Chile to social inclusion and the role in education that the organisations have for society. In the UK and in Romania the emphasis –at least in terms of interaction with "seronegative" society- is placed on health services and on lobbying the authorities.

Representatives in the three countries explain the productive work of dialogue with health and political authorities.
"*Yes, there are such activities, especially ones addressed to the specialists working with PLWHA - infection doctors, psychologists, social workers, employers etc. The activities are: training courses, seminars, workshops, conferences*".
ND/Ro/UNOPA/M.

"We offer *one to one support, this service is well known in the UK; GU* [Genito-Urinary Departments] *have leaflets to let people know*".
CM/UK/THT/M.

4.4.2.2. Perceived achievements

The achievements highlighted by the representatives reflect the crucial role played by PSOs; all of those surveyed have a national presence in their respective countries, with important influence in governmental and health instances and all have been able to improve the quality of life of PLWHA. The latter they have accomplished by helping find solutions and fighting against violations of peoples' rights, and, of equal importance, they have contributed to HIV prevention and the understanding of the process of living with HIV/AIDS by the society in order to support PLWHA.

The manager in **England** maintains the following to be the greatest achievements of that organisation:

"*Being the leading and largest HIV service in the UK, being well known with lots of contacts in Parliament and in the EU government, having influence over HIV legislation, and having fluent and positive feedback from nurses, assistants, GU and ID* [Infectious Diseases Departments] *in the NHS*".

CM/UK/THT/M.

In **Romania** the response is similar:

"*The UNOPA Federation has fought throughout the years to promote and defend the rights of PLWHA in Romania, mainly through sustained advocacy activities at the most important authorities in the HIV/AIDS field (The Ministry of Health, The Ministry of Work, Family and Equality of Chances), but also by monitoring and informing when cases of rights violation occurred, and taking action for solving these cases, and all this is done in order to improve the quality of the life of people living with HIV/AIDS*".

ND/Ro/UNOPA/M.

These achievements reflect the political and public-health impact of each organisation on behalf of PLWHA in the UK and Romania, achieving a better quality of life for their members.

In **Chile,** ASOSIDA highlighted social inclusion as one of its primary achievements:

"*just to mention a few: to have established a model of management based on members' work and needs; to have contributed to the strength of the national network and to projects like the Global Fund; to have installed in a national level the prevention of HIV; to have generated understanding about HIV/AIDS and sexuality; to have implemented peer counselling and help phone-lines; to be the oldest organisation in the country, with active and committed volunteers and to have directly assisted more than 70,000 people".*
ND/Ch/ASOSIDA/M.

Despite the recognition that supplementary work is necessary, each representative clearly defined the essential role played by the organisation, and substantial advances towards organisational targets and PLWHA wellbeing in general.

4.4.2.3. Offered social support

The described achievements are in accordance with the role defined by each organisation: to give support to PLWHA and reduce the levels of discrimination. In this section the role PSOs play as supporters of PLWHA and the ways in which such support is provided are analysed.

In terms of the support role played, the three organisations have a common line of action concerning "*the promotion and defence of people's rights*". These include the right to health care, social inclusion and protection and non-discrimination. This approach is coherent with the importance given to a supportive social network when living with HIV/AIDS, situating stigma and discrimination against PLWHA as a key issue for social functioning and quality of life (Ncama, 2008). In Chile and the UK, the support provided includes sexual minorities' rights. In the UK, this also includes housing and immigration programmes. The roles of each organisation involve:

Chile

"From its foundation the organisation has contributed to the public debate about the right of PLWHA to health (access to HAART) and social inclusion. In this area, we have reinforced networking with other organisations of PLWHA in order to influence public politics towards PLWHA rights".

ND/Ch/ASOSIDA/M.

Romania

"*The organisation plays a key role in promoting and defending the rights of PLWHA in Romania in their relations with the social protection system, and also plays an important role in reducing discrimination and stigma for PLWHA*".

ND/Ro/UNOPA/M.

UK

"*Peer support is the base for higher levels of understanding and the reduction of stigma. This accomplished using different strategies, such as social care, benefits, housing, immigration, health care, stress*

management, positive living, stigma, insulation, women's groups, gay men's groups, one to one support, counselling".
CM/UK/THT/M.

All these activities are upheld by several strategies and procedures that conform to a well-organised programme.

In Romania emphasis is put on:
"*Advocacy/lobbying activities: promoting and respecting the rights of people living with HIV/AIDS; influencing public policy in Romania so that it meets the needs of people living with HIV/AIDS; and high-quality public, medical and social services*".
ND/Ro/UNOPA/M.

In the UK the procedures involve:
"*Volunteers to the programme "Challenging stigma"; sessions about HIV transmission for social services; school talks; this is the right moment to get rid of myths. Also, diagnosis: we are opening more testing clinics in rural areas and for high risk groups".*
CM/UK/THT/M.

In Chile:
"*The organisation counts on a strategic plan orienting internal managing and establishing four strategic targets: Sexual health of GLBTTI, Social management for Organisations, Political and Public influence and the promotion of rights of GLBTTI*".
ND/Ch/ASOSIDA/M.

These activities and strategies, which strive towards the self-proposed organisational role, are strongly related to cultural sensibilities. In the Romanian organisation, for instance, there are no references to GLBTTI people; nor was this mentioned by the National Director of UNOPA. This situation is due to the GLBTTI community not "officially" being a member of UNOPA. This is the result of strong conservatism within Romanian society. Conservatism, although a trait shared among the three countries, seems higher in Romania, and consequently the organisational response is limited in this regard. In the UK and Chile, the GLBTTI community is strong enough to have a clear voice in society and to take action against discrimination, for sexual rights and for sexual health. The difference is in the actions taken to establish visibility; Chile has a more structured programme by which to do so. This difference is mainly due to the origins of the organisations; in the UK THT was directly created for and by PLWHA (also including non-positive people), while in Chile, ASOSIDA was the result of joining different pre-existent associations of GLBTTI, where the focus was on both homosexuality and HIV/AIDS.

In this way support provided is clearly influenced by socio-cultural sensibilities; however, the main advantage of the strategy used by PSOs is the 'tailored' nature of the social support offered. In this way, the strategies focus on the exact needs of PLWHA in each country because they are developed and implemented by PLWHA who take into consideration the specific variables of their own environment.

4.5. Discussion and conclusions

The main contributions of PSOs can be summarised as the improvement of quality of life of PLWHA and the increase in the general population

understanding of the process of living with HIV/AIDS and thus the reduction of stigma and assistance in the prevention of HIV acquisition. This analysis has also established the key role played by PSO in the restructuring of PLWHA's social networks. The positive effects of access to social support have been described as vital in reducing the vulnerability of marginalised or disempowered groups. One proof of this is that in nearly all countries where the HIV epidemic has reversed, community-based mobilisation had a strong role in the response to HIV/AIDS (UNAIDS, 2008).

The three organisations' similarities and differences are equally remarkable. In terms of their similarities, it was not surprising that the three organisations have established the defence of PLWHA rights as a common target. However, the use of different approaches in order to reach that target is likewise significant.

Despite the initial differences in the groups who founded the organisations (parents of children living with the virus in Romania, gay communities in Chile and friends of Terrence Higgins and PLWHA in the UK), the problem identified was the same: social stigma against PLWHA. The three countries have many lessons to share: for instance, the strong legal advocacy and support offered by UNOPA in Romania; the strong movement in Chile based on education about HIV/AIDS; and the emphasis on empowering PLWHA in the UK. However, without a doubt, the support offered to PLWHA by the organisations in the three countries has given people affected by and living with the virus an opportunity to rebuild their social networks of support. Based on studies of the effects on health of social support (Eisenberg, 2003, Fekete, 2009, Kumakech, 2009), PSOs have also helped people to ask that their rights be respected; to learn about and understand

HIV/AIDS; and to keep living with HIV. Because HIV/AIDS "*is not what you are, is what you got*". Every PSO of PLWHA has had a social impact in every country where they exist, and this impact may have a beneficial effect on both the quality of life and the lifespan of PLWHA. Additionally, PSO have helped the general population to prevent and understand HIV/AIDS and in the reduction of discrimination and stigma.

However, as long as fears and ignorance sustain discriminative behaviours against PLWHA, HIV/AIDS will be different from and feared like no other health condition. In this regard, PLWHA organisations have a key role to play as social supporters in the reduction of learned hopelessness behaviours.

The function of THT in the UK as empowering agent is especially meaningful in a context where most PLWHA groups are formed and offered by the health system. This situates members in a passive role, as patients receiving treatment. The support offered by THT aims to empower PLWHA, giving them back the sense of control of their lives; the information provided and the understanding that HIV/AIDS do not transform them into someone else -any more than any other important event in life does-, offers PLWHA members of PSO in the UK the chance to develop numerous skills and, in this aspect, is in accordance with the 'normalisation' strategy of the NHS.

In the case of Romania, the role of a national voice and guardian of PLWHA rights played by UNOPA is absolutely necessary in a country where social and political issues do not guarantee the protection of PLWHA. The existence of UNOPA has given the chance of a supportive environment to thousands of people, in a country that seems not to offer many such

friendly environments for PLWHA. This reality transforms UNOPA into a crucial actor for HIV/AIDS issues in Romanian society. As in no other studied country, the needs UNOPA fulfil show its extremely important role. UNOPA is basically the only opportunity PLWHA in Romania have for peer support. The possibilities for social support created by UNOPA no doubt established a before-and-after situation in HIV/AIDS history in Romania.

In Chile, the function of ASOSIDA as a national network and as an actor in society promoting dialogue based in community education is crucial for the development of this conservative society. In their origins (1986), ASOSIDA faced a similar scenario to the one described in Romania: a conservative society with practically no support for the gay community and, additionally, under a fascist dictatorship. It was within this context that ASOSIDA opened the way for a more inclusive and less discriminative society, radically changing PLWHA history—and all of society—in Chile.

The peer support strategies used by these organisations have meant improvements in quality of life for PLWHA in all three countries. However, the impact of this support on people's health has not been established. These organisations are proposed as expression of the 'living together strategy' aiming to provide PLWHA themselves with the social support often lost at diagnosis.

As in no other health status, and similar to Simbayi (2007), HIV/AIDS still represents a rupture in social relationships. As mentioned by the three representatives; *'social exclusion'* (ND/Ch/ASOSIDA/M)*, 'discrimination against PLWHA'* (ND/Ro/UNOPA/M) and *'social isolation'* (CM/UK/THT/M) are the most common problems PLWHA have to deal with in their respective environments. As a result, often only a few members of the

network closest to a person will be aware of the diagnosis. For this reason, social support is proposed as a crucial factor in HIV/AIDS. Therefore, any source of social support needs to be reinforced and supplied with special emphasis for PLWHA as part of necessarily integrative healthcare. As such, PSO become key health supports for PLWHA. In this regard, research has proposed positive effects on health policies for PLWHA and on national budgets based on cooperative work with groups and institutions of PLWHA, especially when vulnerable groups are included (Wachira, 2010). Unfortunately, the psychosocial support provided by governments still remains at low levels as compared with the needs of PLWHA worldwide; only 27% of countries with a generalised epidemic provide psychological support services (UNGASS, 2008). In low- and middle- income countries, mental disorders represent more than 11% of the total burden of disease; however, on average these countries invest less than 1% of their health budget in mental health services (Patel, 2007).

The organisations included in this study have demonstrated that it is possible to face social, political or religious structures and succeed in giving PLWHA a better opportunity to live with HIV/AIDS and with lower levels of discrimination in their society. Perhaps the most important effects are the opportunity for society to evolve to be more open and to have better understanding of HIV/AIDS, which in turn would help prevent HIV acquisition.

After the analysis of the responses of PSO representatives and healthcare professionals (Chapter Five), it is clear that cultural sensibilities affect the way in which the society perceives and behaves toward PLWHA, as well as the way in which PSOs perceive themselves; establish their targets; choose strategies to achieve those targets; decide the institutional approach to

PLWHA; and decide the role given to their members. These psycho-social factors also affect individuals' health (Greenson, 2008) and the possibility of their integration. Consequently, PSOs must be considered within an integrative approach towards HIV/AIDS.

The main implications of these results are related to the perception of the role played by PSO in the process of living with HIV/AIDS; the benefits have been usually seen in terms of psycho-social support or indirect effects on health such as improving adherence to clinical treatment or to HAART; however, this research proposes the need for a deeper analysis of the possible direct effects of PSO of PLWHA on health status of their members. These organisations are proposed as having a significant and positive impact on individuals' health and cooperative work with these institutions may be considered for an integral approach of PLWHA healthcare. These and further analyses will be expanded in Chapter Nine.

Chapter Five - Health professionals' view

As has been established, living with HIV/AIDS implies a rupture of received and perceived social support (PSS). In Chapter Four, the strategies PLWH use to self-provide social support in the three studied countries were described. This chapter explores the support PLWHA receive from health professionals. Following the line of psychosocial effects of PSO in PLWHA, the support provided by healthcare teams was approached from different perspectives: the effects of healthcare support go far beyond medical care, and have effects on social and psychological areas of PLWHA and of society in general. According to UNAIDS, access to healthcare and support are key elements in the response to the epidemic. To the direct benefits of healthcare are added the reduction of social and economic impact of the epidemic and the boosting of HIV prevention (UNAIDS website). UNAIDS defines 'care and support needs' as: treatment for opportunistic infections, psychological support and social support in terms of social impact and HIV prevention. Accordingly, health care centres usually include within their teams professionals fulfilling the profiles described by the UNAIDS; these are medical doctors, psychologists, social workers and biochemists.

This study focuses on an analysis of cooperative strategies used by healthcare teams in each country to provide social support. Its aims are to obtain data regarding the perspectives of health professionals working with PLWHA in England, Chile and Romania related to the process of living with HIV/AIDS; to elucidate the role played by social support in the relationship between psychological, socio-cultural and immunological factors; and to articulate how socio-cultural sensibilities may influence the choices of specific supportive strategies.

To achieve this target, a qualitative analysis of questionnaires administrated to medical personnel in different countries was conducted. Nine open-ended questionnaires were administered; two in England, three in Chile and four in Romania. Psychologists (two), medical doctors (three), biochemists (two) and social workers (two) were consulted about their general observations concerning individuals living with HIV/AIDS, characteristics of the patients to whom they attend, and their roles as helpers.

Additionally, and as a way to complement the data obtained from healthcare professionals, several reports from international organisations and websites from recognised organisations working in HIV/AIDS were consulted: the Global Fund to fight against AIDS, tuberculosis and malaria [GFATM]; Human Rights Watch [HRW]; United Nations Programme on HIV/AIDS [UNAIDS]; British HIV Association [BHIVA]; Avert; the Terrence Higgins Trust [THT]; UNOPA (Romanian PSO of PLWHA); and ASOSIDA (Chilean PSO of PLWHA).

5.1. Participants and methods

5.1.1. Design

In order to access the different health professionals in the three studied countries, open-ended questionnaires suitable for face-to-face and e-mail administration were developed with the aim of gathering information in four specific areas. Questionnaires were administered to members of healthcare teams at the three hospitals in England, Chile and Romania; these questionnaires focussed on:

- Characteristics of PLWHA: The most common typical features of PLWHA in terms of HIV status from the different professions' points of view. This

variable was included in open-ended questionnaires for medical doctors, psychologists and social workers.

- Discrimination against PLWHA: Professionals were asked about how they perceive the levels of discrimination against PLWHA. Psychologists and social workers were asked about this variable.
- Professionals' approach to PLWHA: The activities that the different professionals undertake for or with their patients. Medical doctors, psychologists, social workers and biochemists were included.
- Opportunities for social support: Any institutional instance of support available for PLWHA in the society in each country, such as social or governmental organisations, legal corpora or governmental health guidelines aiming to protect PLWHAs' rights or improve the quality of life of PLWHA. Psychologists, social workers and biochemists were consulted about the available social support for PLWHA.

Four open-ended questionnaires were created; separate series of questions were developed for each profession. The differences between the four questionnaires refer to diverse emphases given to each variable included; they also refer to different wordings of similar questions used to adapt content to the specific interviewees' area of expertise. Open-ended Questionnaire scripts are available on pages 112-113.

Responses from all professions were compared, and similar and divergent ideas were qualitatively analysed and compared between professionals and countries. *Thematic analysis* was performed across all questionnaires. Comparisons were drawn between the four professions in order to highlight common themes. Additionally, divergent ideas between professions or countries were included in the analysis. In this way, a comparison between

the main characteristics of the approach to PLWHA held by health professionals in England, Chile and Romania was undertaken. In the case of Chile the interviews were translated into English prior to analysis.

5.1.2. Ethics

Ethical approval was granted by the University of Nottingham Research Ethical Committee (REC 1) to carry out the study involving participants living with HIV/AIDS and healthcare team members (Appendix E).

5.1.3. Participants

Population: Psychologists, medical doctors, social workers and biochemists from healthcare teams working with PLWHA in Chile, England and Romania at the three contacted hospitals.
The final sample were nine health professionals; A medical doctor and a social worker in England, from a hospital in the East Midlands; a psychologist, a medical doctor and a biochemist in Chile from a hospital in the Metropolitana region; and a psychologist, a medical doctor, a social worker and a biochemist in Romania from a hospital in the region of Transylvania.

The specific hospitals were chosen for their roles in healthcare for PLWHA in their respective countries or regions. In Chile, the Universidad de Chile Clinical Hospitals is one of the most important health centres in the country and offers healthcare to a high number of PLWHA. In Romania, the Spitalul Boli Infectioase in Cluj-Napoca is recognised by the WHO as one of the largest ambulatory centres of diagnostic and treatment of infectious diseases in Romania (Consiliul Judetean Cluj, Online). This University health centre only treats infectious diseases; therefore, it is the only centre

attending PLWHA in Cluj and receives patients from several cities surrounding Cluj. The City Hospital Campus is part of Nottingham University Hospitals NHS Trust (NUH); it is one of the country's largest and busiest teaching trusts, providing services to 2.5 million people within Nottingham and surrounding communities and therefore serves the greatest concentration of PLWHA in the area (NHS UK, 2010). Based on these data the medical team offering healthcare to PLWHA from these three health centres were targeted to be interviewed for this research, since they are recognised as specialists in their field.

The professionals were coded as follow:

Table 5.1: Code for health professionals

Profession		Country		Sex	
Medical Doctor	MD	Chile	Ch	Female	F
Social Worker	SW	United Kingdom	UK	Male	M
Psychologist	Ps	Romania	Ro		
Biochemist	Bc				

E.g. MD/UK/M refers to the medical doctor from the UK who is male.

Table 5.2: Inclusion – exclusion criteria health professionals

Inclusion	Exclusion
a) Health professionals working with PLWHA	a) Health professional without experience in HIV/AIDS
b) Psychologist, medical doctor, social worker or biochemist	b) Other professionals than described
c) Fluent in English –UK participants	
d) Fluent in English – Romanian participants	c) Does not speak English or Spanish
e) Fluent in Spanish – Chilean participants	

Despite the relevant and unquestionably central role in the fight against HIV/AIDS that each of the included health centres plays, the results of these interviews cannot be considered fully representative for all medical teams working with HIV/AIDS in these countries. However, based on the

expertise of these professionals the collected data offered indeed an accurate picture of the healthcare provided for PLWHA.

Informed consent: The informed consent process was identical to that used with participating representatives of PSO.

5.1.4. Procedure

Open-ended questionnaires were administered to healthcare teams working with PLWHA at the hospitals in England, Romania and Chile. Only three of the four types of health professionals were found in the Chilean healthcare team (medical doctors, psychologists and biochemists); the other health teams included all four mentioned professions. Therefore, eleven interviews were planned; however, two potential interviewees could not be recruited in England (a psychologist and a biochemist). This gave a final sample of nine professionals evaluated. When possible, face-to-face interviews were performed, however, for some participants personal contact was not possible either due to long distances between the researcher and the participants or due to the restricted agenda of the participants. In these cases e-mail administrations were performed instead. None of the interviews were tape-recorded; instead, detailed notes were taken during the interviews in face-to-face modality. Participants in face-to-face interviews were allowed to take as much time as needed to express their answers. They were also given the chance to review previous answers as provided in questionnaires administered by email. In Chile, data were collected using open-ended questionnaires administered by email. In Romania, in-person questionnaires were conducted. In England, the evaluation was carried out by e-mail for the medical doctor and in person for the social worker. Evaluations were conducted in December 2008 in Romania, April 2009 in Chile and May 2009 in England. As with the

interviews performed with spokespersons from PSO of PLWHA in Chapter Two p 44, e-mail interviews offer several benefits as compared to face-to-face interviews. Some specific possible disadvantages for this strategy, such as difficulties in written expression, were not the case for the highly qualified people in the sample.

The questionnaires consisted of open questions related to the topics described in point 5.1.1 (Design) In the case of face-to-face evaluations, participants had the option to verbally express their opinions; detailed notes were taken by the researcher. In the case of e-mail administration participants had a designated space below each question to write their opinion about the specific topic.

In the case of health professionals, except for that of the medical doctor in England, questionnaires were administered in person in England and Romania; however, due to distance, face-to-face evaluations were not possible in Chile. In cases where a face-to-face approach was not possible, electronic evaluations were preformed.

In Romania questionnaires were administered during December 2008. The four interviews were conducted in English by the author and notes were taken during each interview. Romania was the only country with all four types of professional targeted within its healthcare team; it was, therefore, the only country where all four types of professionals were interviewed: one medical doctor (MD/Ro/F), one social worker (SW/Ro/F), one psychologist (Ps/Ro/F) and one biochemist (Bc/Ro/F).

In England three of the targeted professional types were part of the healthcare team at the hospital: a medical doctor, a social worker and a

biochemist. Psychologists are not included in the healthcare team in England; though people are directed to a professional external to the hospital and contact was intended with this professional. Two questionnaires were administered during May 2009, in English. One interview was conducted in person with the social worker (SW/UK/F), during which notes were taken. Another interview was sent by email in accordance with the preferences of the interviewed medical doctor (MD/UK/M). The psychologist and the biochemist in England did not respond to interview requests.

In Chile three questionnaires were sent in Spanish during April and May of 2009. Due to distance, personal contact was not possible with Chilean professionals; therefore, email administrations were performed.

Sample included: One medical doctor (MD/Ch/M), one psychologist (Ps/Ch/F) and one biochemist (Bc/Ch/M). As a result of a different structure of healthcare teams, there was no social worker in the Chilean medical team. In the Chilean hospital, patients who need social services are directed to the social worker of the hospital who does not specialise in HIV/AIDS; most social issues are solved by psychologists or medical doctors.

The information collected was organised in a standard written format. Notes were transcribed to digital format, as were the questionnaires administered by email. In the case of Chile, interview transcripts were translated into English by the researcher with the help of a native English speaker; Romanian and British evaluations were performed in English.

A *thematic analysis* was performed: The responses were grouped according to topics; questions addressed to the same topic for the different professions were compared categorically. Similar responses were grouped based on emerging categories, labels were given to these categories and themes appeared. From these analyses similarities and differences between the studied countries and the remarkable social factors emerged.

5.2. Materials and instruments

Different questionnaires were used for each profession. However, some questions were used in more than one interview script and others were adapted to the specific area when appropriate. These differences improved the quality and quantity of information elicited from the respective areas of expertise of each professional interviewed.

The items included in each interview script corresponded to a series of variables and targets defined for each profession included in the sample. Every interview included the following statement concerning information about the research, the use of the information and confidentiality issues:

Statement

This interview is part of a PhD research programme carried out at The University of Nottingham, Nottingham, England. The information provided will be seen only by the researcher and his supervisors. **Permission is requested** to interviewee **to use quotations from the questionnaire** in the data analysis of the final Doctoral Thesis. All personal information is subject to the University of Nottingham ethical confidentiality guidelines and laws.

Professionals were asked about general and specific characteristics of PLWHA in their countries; the dynamics of discrimination against PLWHA; the strategies that their particular country is taking to deal with HIV/AIDS; and the characteristics of their personal approach to patients as health care team members. The questionnaires read as follows:

5.2.1. Medical doctors' questionnaire script

1. In your experience, what are the most common medical characteristics of PLWHA in (country)? (HIV stage of notification, associated diseases, reasons for performing an HIV test, etc)
2. In your opinion, how are peoples' levels of understanding in terms of the risk of acquisition of HIV?
3. What is the diagnosis process here in the Hospital?
4. What are the routine medical tests for someone seropositive in (country)?
5. In your experience, what are the levels of treatment adherence (HAART) in PLWHA in (country)? Why is this so?
6. How are the levels of ARV resistance in the (nationality) population?
7. Which are the greatest difficulties in the treatment of PLWHA in (country)?

5.2.2. Social workers' questionnaire script

1. In your experience and from a social point of view, what are the characteristics of PLWHA in (country)?
2. What is the situation in terms of stigma and discrimination in HIV/AIDS in (country)?
3. What are (roughly) the general legal indications for the notification process?
4. What is done after notification? Are there any guidelines or programmes from the Health System? Social evaluations?
5. What is the training process, if any, for health team to the notification process?
6. What are the most important social rights in terms of HIV/AIDS in (country)? (Social, medical, etc, if any).

7. What are the opportunities for social support for PLWHA in (country) and how is this support provided? (Social or psychological programmes, Organisations of PLWHA, etc.)
8. How do prevention programmes for HIV acquisition work in (country)? Which are in place now?
9. What are the indications about relatives, couples or friends of the notified patients? Is there any programme available for them?

5.2.3. Psychologists' questionnaire script

1. In your experience and from a psychological point of view, what are the characteristics of PLWHA in (country)?
2. What is the situation in terms of stigma and discrimination on HIV/AIDS in (country)?
3. How is the secrecy around an HIV diagnosis managed by patients?
4. What is the diagnosis process here in the Hospital?
5. What is done after notification? Are there any guidelines or programmes from the Health System? Psychological measurements?
6. What training, if any, is given to health teams about the notification process?
7. What are the opportunities for social support for PLWHA in (country) and how is this support provided? (Social or psychological programmes, Organisations of PLWHA, etc.)
8. What are the indications about relatives, couples or friends of the HIV-positive notified patients?

5.2.4. Biochemists' questionnaire script

1. Are there legal indications for the HIV detection process?
2. Which tests are performed to detect the virus?
3. How long is the notification process from the first test until the diagnosis is given?
4. Which are the tests used for CD4+ lymphocytes study?
5. Which are the tests used for viral load level study?
6. Which are the tests used for ARV resistance study?
7. What is the process for children born to a seropositive mother? How long does it take to know the serological status of the children?

5.3. Results - Main themes and cross-cultural perspective

This section includes the main themes identified from the *thematic analysis* of the questionnaires across the three countries. Four themes were identified from the responses to the questionnaires related to the process of living with HIV/AIDS in Romania, England and Chile: cultural factors; understanding, prejudice and discrimination in HIV/AIDS; avoidance; and anxiety. Additionally, distinctive features related to cross-cultural characteristics are analysed: clinical features; strategies used to approach PLWHA in each country; and how each country's specific approach is reflected in the diagnosis process and the offered support.

5.3.1. Main themes

5.3.1.1. Cultural factors

Socio-historical events related to the emergence of HIV/AIDS as a public health issue appear as a common characteristic in each of the three countries. Together with certain social factors these events served to maintain discrimination against PLWHA. The following example serves as contextualisation: In Romania, according to the Human Rights Watch [HRW] Report (2006), in the late 1980s and early 1990s, more than 10,000 newly born and very young children (not older than two) were infected through medical negligence (See details in Chapter Four). Approximately 7200 of these children—now teenagers—are still living (the exact number of victims is not given in the consulted documents). One of the Romanian responses to this situation has been 100% HAART coverage. However, these children remain strongly discriminated against. According the Romanian psychologist and social worker and as corroborated by HRW (2006) most of the children were isolated by their parents and educational system, exacerbating illiteracy and poverty. When asked about the

greatest difficulties in treating PLWHA in Romania, the medical doctor responded:

"*The level of education; they do not understand the seriousness of the problem* [HIV/AIDS]*; counselling is so important for parents* [to understand] *the need for following the treatment*".
MD/Ro/F.

In the UK, the process of discrimination began with the first cases in the early 1980s. Despite the ways of HIV acquisition being quickly discovered and disseminated through the health community, discrimination on the part of the public, as well as that of public officials, persisted. For example, firemen were instructed not to give mouth-to-mouth resuscitation to injured people who might be gay. Nurses at Princes Charles Hospital warned that they would take legal action against Health Authorities if they were not informed when treating AIDS patients (Avert, [2009] online).

This led to a rapid reaction within society and the government. Advocacy groups and strong information campaigns were launched in an attempt to clarify myths surrounding HIV/AIDS. Despite strong opposition from conservative corners, these efforts were effective and situated HIV/AIDS as a topic of discussion (Avert, online). Even though situations like the ones described above have diminished in UK society, others social factors have appeared. The interviewed social worker and physician coincide in describing social factors as a crucial aspect on PLWHA treatment;

"95% of the patients under our care are very good at adherence. This will be because we have few intravenous drug users and others with chaotic life styles. Social factors are major problems. Those who are intravenous drug

users or have chaotic life styles for other reasons are difficult to follow up and treat. Some of our patients are asylum seekers. They have little money and find it difficult to afford food and basic needs for healthy living."
MD/UK/M.

The medical doctor in Chile describes a similar scenario, citing adherence and subsequently treatment success as being strongly influenced by socio-cultural factors.

"Their behaviour is diverse, and in general is related to their socio-cultural level [education level, understanding, knowledge, access to culture]; *the support of the healthcare team and counselling is so important. In general, and based on the National Cohort, I would say adherence in our country is very good".*
MD/Ch/M.

Despite its economic and socio-cultural development since the end of Pinochet dictatorship in 1989, Chile is a traditional society, marked by the still considerable (though declining) influence of the Roman Catholic Church. This might explain the focus on "opening the dialogue" expressed in information campaigns.

It is interesting to compare some socio-political similarities between Romania and Chile. Both countries saw the end of bloody dictatorships in 1989, establishing democratic systems in 1990. Nevertheless, these dictatorships were based on opposing, though similarly extreme political ideologies (In Chile, 16 years under a fascist military regime; In Romania, 30 years of a totalitarian Communist regime, pre-dated by another 20 years of other dictatorial systems, dating back to 1938).

5.3.1.2. Understanding, prejudices and discrimination in HIV/AIDS

These three factors (understanding about HIV/AIDS, prejudice and discrimination) are well connected and affect PLWHA in several ways. As well as the obvious relationship between the factors (lack of understanding about HIV/AIDS as the base for prejudices sustaining discrimination against PLWHA), the analysis of the responses given by the health professionals also shows another approach: a higher perception of 'risk' is connected to a higher understanding of HIV/AIDS among those 'at risk' and might be linked to preventive behaviours; and higher prejudices and lack of understanding of HIV/AIDS issues among those 'not at risk' can involve lower preventive behaviours, and, thus, a higher risk of HIV acquisition.

"*This is very variable. Many Africans speak more openly about HIV than their Caucasian counterparts and are aware of heterosexual transmission. However there is still a perception that if someone is feeling well they will not have HIV. There is therefore an underestimation of risk".*
MD/UK/M.

Such underestimation is a common observation of all interviewed:
"Not very high [HIV/AIDS understanding of general population]*, adolescents* [considered a risk group] *have better knowledge".*
MD/Ro/F.

Those groups perceived to be at higher risk in the different countries seem to have higher levels of understanding about HIV. This may have an impact on the epidemic. For instance, the increase in heterosexual people acquiring the virus may be related to a perceived lack of risk.

"Lots of assumptions and ignorance; there are not [enough] *Governmental programmes".*
SW/UK/F.

"*In Chile there is still such a lack of understanding regarding what living with HIV/AIDS means from a health point of view. Most of the people do not know the difference between living with HIV and having AIDS."*
Ps/Ch/F.

These were the most common answers describing individuals' general understanding about HIV/AIDS. These answers were strongly connected with prejudices. For instance, that HIV/AIDS is a disease associated with specific sexual practices or sexual conditions is still a common misconception, affirms a Chilean psychologist:

"*Many continue to think of it as a mortal disease still associated to a certain type of sexual practices*".
Ps/Ch/F.

This belief reaffirms individuals' tendencies to see themselves as "not at risk", and may result in fewer or no precautions against HIV acquisition. Recent studies have shown similar results in this matter connecting attitudes of stigmatisation with higher complacency toward one's personal risk status, leading to a reduction of protections against acquiring HIV (Riley, 2010).

"*In general* [understanding] *is not good, as the prevention campaigns have not been so appropriate. And on the other hand, the population sees this*

problem as alien, until it touches them. But yes, there is more information among people in groups with higher risk acquisition".
MD/Ch/M.

These side effects of discrimination and level of understanding or information available about HIV/AIDS may result in people seeing themselves as outside of the "high-risk groups" and therefore considering safety measures to be personally unnecessary, thereby increasing their chances of acquiring the virus. Believing that they themselves are not at risk of HIV, people may fail to check for possible virus acquisition when "risky behaviours" or early indications are present. This may seriously affect their health status and prognosis. Based on these responses, little progress has been made in the general population about the attitude towards PLWHA. On the other hand, 'at-risk groups' seem to have better understanding about acquisition paths and preventive behaviours.

Discrimination against PLWHA was commonly mentioned by interviewees in each country, and was linked to understanding and prejudices. Social stigma, compounded by a lack of information about HIV/AIDS, seems to be the common denominator for the HIV/AIDS dynamic.

Higher reported discrimination was found in Romania than in England and in Chile. In this conservative society many factors, such as poverty, lack of information, and prejudice, all contributed to an unfriendly environment for PLWHA (HRW, 2006). However, PLWHA also have difficulties in England. Some of those interviewed in England and Romania declare health teams as one of the places where PLWHA suffer discrimination.

"*I was really surprised by the levels of discrimination; they are high even within the health professional community. Lots of assumptions and ignorance; there are no governmental programs dealing with this".*
SW/UK/F.

"The m*ost discrimination is carried out in health places. Dentists or surgeons will not treat PLWHA because they may lose seronegative clients or because of the risk of acquiring the virus*".
Ps/Ro/F.

The discrimination against PLWHA by health care teams opens a critical and conflict-ridden area in the process of living with HIV/AIDS. Discriminative behaviours from health professionals against PLWHA were described by health team members in England and Romania and by PSO in Chile. In this situation UK was related to ignorance and lack of governmental information campaigns. In Romania it was also related to a lack of information; however, it was also based on the potential reaction of seronegative patients if an HIV+ person were found to have been treated in the same private clinic. In Chile, the National Director of ASOSIDA mentioned lack of support from health and public services for the needs of the GLBTTI (Gay, lesbian, bisexual, transgender, transsexual and intersex) population (details in Chapter Four). With regards to this, the latest research indicates that healthcare personnel play a more relevant role than previously believed in reducing the perceived stigma of PLWHA (Colbert, 2010).

However, discrimination does not come from seronegative people only. Most of those interviewed also described self-discrimination as an important and common factor among their patients.

"Many continue to think of it as a mortal disease still associated with certain types of sexual practices. This causes PLWHA to discriminate against and stigmatise themselves based, of course, on the perceptions they have about society, and those of their close contacts (friends, family, working place, etc.) *whom they use to confirm these prejudices".*
Ps/Ch/F.

The conclusion in terms of understanding, discrimination and prejudices against PLWHA is clear and similar in the three studied countries. Despite cultural differences, all three countries present low levels of understanding and relatively high levels of discrimination and prejudice against PLWHA. These levels have been related with the perceived "level of risk" of HIV acquisition.

5.3.1.3. Avoidance

Avoidance as coping strategy was commonly described in terms of people's reactions to the diagnosis and to HIV/AIDS in general; however, it seems to have different expressions in the different countries.

"*They use avoidance as the most common coping strategy; refusing to talk and even been informed about it."*
Ps/Ro/F.

"When it comes to coping strategies, a wide variety it can be seen, depending mostly on personality and social characteristics. However, striking avoidance strategies are shown by some of the patients from the moment of the blood test, the diagnosis, and through medical controls and the adherence to treatment. Even if this is not frequent, it is important to

highlight due to the effects this can have on PLWHAs' health and for the prevention of HIV transmission."

Ps/Ch/F.

This difference observed by mental health professionals may be related to discrimination levels in their respective countries. In a more open society, Chile compared with Romania for instance, one might find it easier to use coping strategies to approach problems than to avoid them; at least theoretically there are fewer social factors blocking more open expression about conflictive subjects like HIV/AIDS and homosexuality-related issues. This coincides with results obtained in the evaluation of PLWHA in Chile showing low levels of avoidance as coping strategy (Chapter Six). It is also striking that no records were found concerning prosecution over the infection of the Romanian children. According to HRW (2006), the high levels of discrimination in Romania are disproportionate to the low number of reports or legal processes against these crimes. HRW maintains as a factor in this situation the poor confidentiality levels when criminal charges are presented; the meagre success that these judgments have due to high levels of corruption; and the fact that any resulting fine goes to the state and not to the victims. In the light of these facts, avoidance may just be an adaptive behaviour in the order of learned hopelessness.

5.3.1.4. Anxiety

Anxiety is another described consequence of the dynamics of discrimination (coming from outsiders or from the person him/herself). The British social worker provided a detailed analysis of the sorts of anxieties observed in different groups at the point of diagnosis. She describes anxiety as one of the common factors for PLWHA.

"Anxiety is a common factor, different groups have different anxieties. Among Africans, anxiety is related to others knowing, but with a higher concentration on themselves and higher intolerance against themselves. In the case of homo-bisexual men: they usually are married and are trying to explain how they got HIV, trying to make up an excuse. Among heterosexual women, the most common disorder is depression and anxiety. Among homosexual men, there is the worry about what others may know, but only among new diagnosed cases; the less-recently diagnosed do not worry anymore".
SW/UK/F.

She describes higher levels of intolerance among Africans immigrants in the UK (against themselves) relative to among Caucasians, and anxiety as the common denominator of any group living with HIV. Similar descriptions of anxiety were expressed by professionals from Chile, Romania, and the U.K.:

"They [PLWHA] *are very afraid for others to know their condition; such anxiety is very common".*
Ps/Ro/F.

"People gothrough this health process very alone, because they decide not to tell anyone else. ...for many people this condition is still a heavy social stigma and the anxiety resulting from this causes some of them to cut off their social networks like family, friends or relationships".
Ps/Ch/F.

5.3.2. Cross-cultural differences

5.3.2.1. Patients' clinical characteristics

In this section the most common medical characteristics of PLWHA described by medical doctors in all three countries are presented; late diagnosis and specific opportunistic diseases were the most widely mentioned.

"*In general terms patients are making their debut* [the moment the diagnostic is discovered] *in the advanced stages of their diagnosis* [HIV infection process]*; B2, B3, C2 or C3*" [Details of HIV/AIDS CDC Classification in Chapter One, Table 1.1, page. 22].
MD/Ch/M.

"*My experience is mostly with late presenters to hospital with opportunistic infections and sometimes malignancy*. *Many patients presenting in this way originate from Africa*".
MD/UK/M.

"*The most common is the stage in which the patients are diagnosed; B or C with strong clinical symptoms*".
MD/Ro/F.

The interviewees state that the diagnosis is commonly made in the late second (B2, B3) or in the third (AIDS; C1, C2 or C3) HIV infection stage. For details of the stages of the HIV infection, see Appendix A. As seen, one of the reasons mentioned for this late diagnosis is the stage at which patients present themselves to check their serologic state. As described, this can be associated to the level of information people have about when a

check is needed and also to discrimination and prejudice, as people might feel afraid to take the test if they are worried about being socially exposed in the place the HIV test is performed.

"*It is rare that the diagnosis is made during seroconversion or the asymptomatic stage; the usual situation is due to manifestations that are indicative of pathology the moment that the test is performed*". MD/Ch/M.

In instances when the HIV infection is discovered due to secondary opportunistic infections arising as a result of severe immunological deterioration, the survival of the patients can be severely reduced when compared with patients diagnosed at an earlier stage (ECDC, 2010).

The high rate of late-stage diagnoses in the UK has been partially attributed to the presence of a health system that is structured in primary and secondary healthcare stages: In the UK, in order to be seen by a specialist, patients are first required to see a GP, thereby reducing or eliminating, according to Burns (2008), opportunities for earlier HIV diagnosis. The same author cites individuals' concerns related to HIV tests, including lack of confidentiality, discrimination, and a lack of information about HIV. This extends the reasons for late HIV diagnosis in the UK to a social and structural dimension. However, whatever the reasons are for this phenomenon, it indicates another similar factor between these countries. Since the time of diagnosis can strongly modify HIV evolution as an infection process, cross-cultural characteristics and social characteristics can be crucial factors for earlier HIV diagnosis and therefore for quality of life and lifespan for PLWHA.

5.3.2.2. Country-based strategies for dealing with HIV/AIDS

Established from the analysis of the collected data from healthcare professionals, this factor constitutes one of the most crucial differences between the studied health centres in Chile, England and Romania. The three centres have been instructed in different approaches to HIV/AIDS by their respective national health system authorities, with different socio-cultural characteristics producing different strategies in order to reach a similar goal—PLWHA healthcare. Basically, these differences are related to the emphasis given to the condition of "living with the virus". England is in the process of normalising this condition by treating PLWHA as any other chronic disease. This is a striking contrast to the status HIV has as a "special" condition in Romania and Chile. This section explores this dynamic, among others, and analyses the impact of these differences on the process of living with HIV in Chile, England and Romania.

The three countries have important similarities in terms of HIV/AIDS epidemiology. Rates of infection are relatively low and under control. The main path of acquisition is currently sexual. Patients are mostly homobisexual men, but with increasing numbers (and proportionally higher numbers) of heterosexual and female acquisition in recent years (see details in Chapter One). These macro-scale features make a comparison of these countries possible. However, the strategies adopted to deal with the HIV/AIDS epidemic are different in all three of them:

In Romania the strategies in use are strongly influenced by the children infected in the 1980s-1990s. Most PLWHA are seen as victims and receive several benefits from the central government.

There are two laws giving benefits to them [PLWHA]. *One specifically for HIV (Nº 584) gives them a food loan, enough to live in Romania. Moreover, they receive another pension (Law Nº 448) for people with disabilities due to chronic diseases. The amount of this one depends on the level of advancement of the disease, and it is not limited to people with HIV.* SW/Ro/F.

Additionally, PLWHA in Romania (as well as the UK and Chile) receive medical treatment, periodical monitory tests, and 100% HAART coverage.

The strategies in operation are geared towards a medical healthcare approach. With the Global Fund project, multidisciplinary teams were initiated, training was provided and information campaigns were launched. The teams are still in operation; their request for initial funding includes medical doctors, psychologists, social workers, nurses and laboratory personnel (GFATM, 2008).

There is also a voluntary sector offering support: the National Union of Organisations of People affected by HIV/AIDS (UNOPA, from Romanian acronym; www.unopa.ro). This organisation was an initiative of the parents of the children infected during 1986-91.

In England the approach is based on a different approach. After many years of governmental plans, multidisciplinary teams with a range of professionals, and pre and post-test counselling, the strategy is changing towards a "normalisation" of the HIV/AIDS disease.

"HIV is like other conditions. There was a normalization process. Years ago, there was pre and post-test counselling for the diagnosis, lots of people were involved in the processes. Now there are fewer involved staff".
SW/UK/F.

There is now medical, social, and psychological support for PLWHA; however, this support is also available for any chronic disease. Even though HIV/AIDS can potentially cause disability, in England (as in most of the countries with full HAART coverage) it is no longer considered among the disabling or mortal diseases. This is based on 100% HAART coverage, and on the resulting increase in life expectancy and improvement in quality of life. While PLWHA in the UK still receive pensions, these may disappear over time. The UK is conducting campaigns focusing on prevention, and specifically on sexual education starting in schools.

"We're putting lots of money into awareness, especially for young people, sex prevention, teaching them to be as safe as possible. However, sex education can be banned by school directors".
SW/UK/F.

The normalisation strategy is based on hospital support via multidisciplinary teams (NHS). In parallel, there are National PSO of PLWHA, based on voluntary work, which provide peer support, information and advocacy. Terrence Higgins Trust (THT) is the biggest PSO in the UK (www.tht.org.uk).

In Chile HIV/AIDS strategies can be defined as a mixture of the strategies performed in Romania and England. Chile shares with Romania a special healthcare management for PLWHA; however, as in England, the emphasis

has been placed on education to reduce stigma. Chile, unlike any of the other studied countries, has strong laws regulating PLWHA's rights and diagnostic processes.

"The process is included in the law 19.799 and establishes Norms Relative to Human Immuno Deficiency Virus and to its Regulation, approved by Decree No 182, in 2005".
Bc/Ch/M.

As in Romania and the UK, HAART is 100% covered, as are medical care, psychological support, and specific tests. However, PLWHA do not receive governmental pensions, as they do in the UK and Romania.

"The results of the exams for HIV detection will be given confidentially and only to the person concerned. The person interested in taking the exams must present consent prior to taking a [blood] *sample. The consent must be signed by the patient or his/her legal guardian. There must be a process of pre- and post-test counselling".*
Bc/Ch/M.

"The result [HIV diagnosis] *is given by a psychologist through an individual counselling process that must obey regulations, characteristics and targets indicated by the Health Ministry through its strategy for the integral care of people living with HIV/AIDS".*
Ps/Ch/F.

There are also yearly prevention campaigns and sexual educational programmes run through secondary schools.

"The social support is implemented by the Health Sector in coordination with other state offices and with social organisations working in the area. In this regard it is important to mention an important network of social organisations at national level, especially VIVO POSITIVO and ASOSIDA".
PS/Ch/F.

There is a strong and organised civil society pressuring and helping the government to ensure that the rights of PLWHA are respected, and that information campaigns are clear. The society also produces their own campaigns. The main strategies are education and opening the dialog over HIV/AIDS.

Beyond these different approaches in the three countries, similar basic tasks are targeted during the diagnostic process: giving "real" and up-to-date information about HIV/AIDS; providing emotional support to the patient and, if possible, to his/her partner; promoting contact with their innermost social networks; informing them about the social benefits available; and starting subsequent medical treatment.

"Health advice: They give information about benefits for physical disabilities; try to make sure that the social and emotional areas are ok: housing, medication. We try to look after them, to assess and refer them to the right services, working with THT, psychologists, and addiction treatment specialists".
SW/UK/F.

"We try to provide emotional support through counselling if necessary, and to give information about HIV/AIDS (among others; prevention, self-care,

treatment and transmission ways), individuals' health rights, as well as to enquire about and promote social and family networks of support".
Ps/Ch/F.

"Sometimes it is the medical doctor [who gives the diagnosis]*, sometimes it is me or my colleagues* [social workers]*, but we* [psychologist and social workers] *always talk with them. We offer emotional support."*
Ps/Ro/F.

These data provide a base from which to establish different approaches in healthcare strategies in Chile, Romania and the UK. The UK, through the National Health Service, is in the process of 'normalisation' of HIV/AIDS condition (promoting its treatment as one among other chronic diseases). Similar strategies appear from PSO of PLWHA, such as THT; however, cooperative work between the NHS and PSO does not appear as an important factor in this strategy. Additionally, and despite conducting awareness programmes, there are still low levels of understanding about HIV/AIDS, strong discrimination, and the perception among PLWHA that they still need to hide their diagnosis from those around them. In Romania there are two lines of action, one from the central government, which is oriented to medical care and the second from the PSO for PLWHA, UNOPA, which also performs an assistance role, without cooperative work between the two. Despite their perception as victims, most PLWHA are still strongly discriminated against and no prevention or information campaigns have been performed within the last five years.

"There were [prevention programmes] *five or six years ago; now on the 1st of December of every year, an organisation of medical students puts*

together an event, give information to other students, and hands out booklets with information".

SW/Ro/F.

In Chile, as well as in the UK and Romania, the strategy has been focused on assistance but with a decisive role for PSO. The current strategy involves cooperative work between the PSO of PLWHA and the Chilean health system. However, and despite yearly campaigns, the perception of healthcare professionals still displays a considerable lack of understanding about HIV/AIDS from most of the population.

For details of the role played for PSO of PLWHA in the fight against HIV/AIDS in each country see Chapter Four.

5.3.2.3. Diagnosis and support

The way in which the HIV diagnosis is given also has different manifestations in the three countries.

In Romania the diagnosis is given by a medical doctor, at which point information and initial support is provided. If the medical doctor considers it necessary (which is in most cases), the psychologist and social workers contact the patient, offering specific information related to their area, as well as emotional support.

"The doctors give the diagnosis. This is horrible, in my experience. Information about infection, transmission and general information is given.

Later the psychologist and social workers help in the counselling, explaining adherence, TARV and other non-medical variables in depth. This is the way this hospital works".

MD/Ro/F.

However, in some cases the patient refuses to allow more people to know the diagnosis, preferring to keep the information only with the medical doctor. Despite this, in most the cases, the patients receive social and psychological support in a section of the hospital dedicated to HIV/AIDS.

In England, the diagnosis is given either by a medical doctor or a nurse-specialist in HIV/AIDS.

"The doctors and HIV specialist nurse in our department are competent to counsel and organise a test. We will send blood to our laboratory and feedback the result to the patient when it is available".

MD/UK/M.

As in Romania, information and support are offered. Patients are treated by the hospital team working with HIV/AIDS at Infection Diseases, or Genito-Urinary sections, depending on the specific health condition affecting the person. This reflects the purpose of normalisation of HIV/AIDS, treated as "just one more" among other sexual or auto-immune diseases.

In Chile

"*The diagnosis is given by a psychologist thorough an individual counselling process*".

Ps/Ch/F.

The process of diagnosis includes pre- and post-test counselling. Information and psychological support is given, and after the diagnosis the patient is scheduled for a second interview within 48 hours and, if they have not already, medical and administrative processes are begun. As in Romania, there is one section in the hospital that treats PLWHA, though not exclusively. Common to all three countries is the focus on social contact, asking the patients about their social networks (couple, friends, family, etc.) and promoting a patient's contact with at least one of their closest friends of family members.

As can be seen, the UK differs from Romania and Chile in the emphasis given to HIV/AIDS as just one among many other health conditions. The diagnosis is given with no especial procedures when compared with diagnosis of other diseases. On the other hand, a highly detailed procedure is conducted in Chile and only professionals qualified in counselling can give such diagnosis. In Romania medical doctors are assisted by psychologists and social workers for a complete support.

5.4. Discussion

In terms of clinical management, the three countries have a strong emphasis on clinical assistance, supplying free health care, drug treatment and clinical tests. In this regard a difference is seen in Chile where, in the context of a Global Fund Project, PSO of PLWHA have an important role in how the epidemic is faced, with groups composed of Health Ministry members, PSOs of PLWHA national directors, international organisations and university representatives working cooperatively to find better ways to deal with HIV/AIDS. This gives HIV/AIDS management in Chile a notoriously different status compared with any other disease, which can

bring numerous benefits, such as a stronger control in terms of discrimination, a fast-track for PSO of PLWHA to communicate with governmental health institutions and more 'realistic' awareness campaigns. Nevertheless, in the opinion of Chilean health professionals, the level of awareness resulting from the preventive campaigns is still low.

In the case of Romania, health care teams are the result of a work of international cooperation (the Global Fund Project) and most of the healthcare teams in the country are composed of multidisciplinary professionals including medical doctors, psychologists, social workers, biochemists and nurses, all trained in HIV/AIDS as part of a coordinated programme. This established a significant difference to Chile and England where the training for healthcare teams is an activity performed internally for each health centre.

As mentioned, in terms of the strategy behind healthcare for PLWHA, the UK established a remarkable difference in trying to 'normalise' HIV/AIDS. As the social worker from England noted, *"HIV is like other conditions. There was a normalization process"*. Based on these data, the UK seems to be aiming for the 'next stage' in PLWHA healthcare, removing from HIV/AIDS the halo of a special health condition. The classification of HIV/AIDS as chronic disease—based on 100% HAART coverage—makes HIV/AIDS no different from other chronic health conditions that with the appropriate treatment do not represent a risk to life. In the view of the current analysis, England is the only country of the three in the process of establishing HIV/AIDS healthcare under this logic. This may have strong impacts on the specific population, one of the most beneficial of which is the perception of being affected by an acute, but non-mortal disease, which may in turn have significant effects on patients' perception and

behaviour. Nevertheless, following the view of the British interviewees, England has a long way to go through education, information and discrimination issues before HIV/AIDS is seen as an acute but treatable and 'one more' health condition.

In terms of prejudice and discrimination the interviewees from England, Chile and Romania have a similar opinion: there is a strong discrimination against PLWHA and this discrimination is associated with lack of understanding about the HIV/AIDS dynamic. However, discriminatory behaviours also come from health professionals, a sector in which a higher level of information may be expected—but not necessary understanding.

Closely related to prejudices about and lack of understanding of HIV/AIDS was the description of 'at risk' and 'out of risk' populations. A higher level of understanding about the HIV/AIDS dynamic among 'at risk' populations was described by health teams in the three countries. Paradoxically, this population was described having more information about HIV/AIDS, which may result in higher protective behaviours to prevent HIV acquisition. This situation may have an impact on the epidemic. For instance, the notorious increase in heterosexuals acquiring the virus may be related to this perceived lack of risk.

Social factors, such as educational level, the use of drugs or socio-political circumstances (such as the case of asylum seekers in the UK), were mentioned in England, Chile and Romania as factors affecting healthcare of PLWHA. These social factors may affect adherence to treatment and control attendance, affecting the effectiveness of healthcare, exposing PLWHA to higher levels of risky behaviours because of isolation from their families or social support networks(UNAIDS, 2008). Along the same lines, avoidance

was described as one of the most common strategies for facing the HIV diagnosis and the extent of its utilisation was linked to discrimination processes against PLWHA.

In terms of similarities, there were several common factors between these three countries. Cultural factors such as conservatism are high in Chile, Romania and England; all three countries showed a lack of understanding of HIV/AIDS and discriminative behaviour against PLWHA. Avoidance and anxiety were commonly described as the most typical reaction of individuals dealing with HIV/AIDS. This scenario seems to be coherent with avoidance of HIV screening resulting in late diagnosis, most often in the final stage of HIV infection (AIDS stage). However, these similarities are not expressed through similar approaches to HIV/AIDS by healthcare teams. Each country has specific problems and advantages compared with the other ones and the normalisation strategy used in the UK, the inclusion of PSO to deal with HIV/AIDS in Chile and the multidisciplinary teams in Romania are strategies that can be used in other countries to advance in their fight against HIV/AIDS.

Based on the general background given by the analysis of PSO of PLWHA and healthcare teams, in the following chapters, a deeper analysis of PLWHA members and non-members of PSO is conducted. The emphasis here is placed on the psychological, social and immunological characteristics of PLWHA; the relationship between these variables; and the impact these variables have on HIV/AIDS. The next chapter provides a complement to the two previous chapters and emphasises the individual impact of social support on HIV/AIDS evolution in Chile, England and Romania.

Chapter Six: Psycho-immune variables of PLWHA

Taking as their starting point the background provided by the study of the social, psychological and medical support offered by PSOs of PLWHA and healthcare teams in Romania, England and Chile, the following chapters move from these general and systematic provisions of support to a specific analysis of PLWHA and the expression of psychological, social and immunological variables (present Chapter), the pilot of an Intervention Programme (Chapter Seven), and the observed effects of this intervention (Chapter Eight). This chapter focuses on the study of PLWHA in Chile.

The data analysis explores the relationship between social support – especially its perception- and biological function based on immune system functioning (CD4+ lymphocytes). Within this chapter the following research question is addressed:

What is the correlation between PSS, anxiety, depression, coping strategies (approach, avoidance, emotional regulation and reappraisal), CD4+ lymphocytes, VLL and HAART in PLWHA from Chile, and how are these variables and their correlations expressed?

6.1. Participants and methods

To answer the question above, and to analyse the evolution over time of the studied variables in their correlation with immunological parameters, a longitudinal evaluation of a self-selected sample in a 'within participant' model was carried out with evaluations every three months over a period of a year. Five psychological (PSS [CPAS], anxiety and depression [HADS] and coping strategies [FDC]) and immunological (CD4+ lymphocytes)

assessments of PLWHA non-members of PSOs were performed and clinical data were collected in Chile. Participants were recruited at Universidad de Chile Clinical Hospital. Due to the size of the sample and not expectation of normal distributed variables, a non-parametric analysis was chosen and a Wilcoxon test was performed.

6.1.1. Participants

Population: PLWHA in Chile, men and women between 18 and 60 years, diagnosed as HIV+ by the Instituto de Salud Pública (ISP [Institute of Public Health]) in Chile before 31st April 2009.

Informed consent: Participants provided written informed consent (Appendix J). The researcher explained the details of the study and provided a Participant Information Sheet (Appendix K), ensuring that each participant had sufficient time to consider his or her inclusion in the study. The investigator answered all questions concerning participants' inclusion in the study. Participants received cumulative feedback for each evaluation in which they took part.

Participants were recruited from the Universidad de Chile Clinical Hospital in Santiago. In order to invite participants to take part in the study, to give detailed information about their roles and possible benefits of including themselves in the research, as well as increasing adherence to the study, individual meetings were carried out with each of the potential participants. Forty-seven patients willing to be included signed the Informed Consent Form and were informed that they would be contacted via email by the researcher as a starting point of the study. Replies were obtained from 25 participants across the five evaluation points. Fifty-three evaluations were

completed with attrition of participants over time; 24 responses at the first evaluation (51.06% of adherence), nine at the second (19.15% of answers), 10 at the third (21.28% of answers) and five (10.64%) at the fourth and fifth evaluations.

Table 6.1: Inclusion – exclusion criteria for PLWHA

Inclusion	Exclusion
a) Men and women between 18 and 60 years old	a) To be seronegative for HIV
b) Diagnosed as HIV+ by the Instituto de Salud Pública (ISP) in Chile before 31st April 2009	b) To be in the symptomatic stage of HIV evolution (AIDS) according to the CDC criteria (1993) and be unable to answer psychological tests because of acute opportunistic diseases
c) Fluent in Spanish	c) To be unable to provide informed consent.
	d) To lack internet access.

6.2. Instruments

6.2.1. Psychological questionnaires

For perceived social support (PSS), the Cortés (2003) 'Cuestionario Percepción del Apoyo Social' (CPAS) was translated, piloted and adapted as 'Questionnaire of Perceived Social Support' (CPAS); for anxiety and depression the Zigmond, (1983) Hospital and Anxiety and Depression Scale (HADS); and coping abilities (approach, avoidance, emotional regulation and reappraisal) were assessed using the Ferguson and Cox, (1997) Functional Dimensions of Coping (FDC).

CPAS (from Spanish acronym): The Questionnaire of Perceived Social Support. PSS is an important variable which influences health status. (Turner-Cobb, 2000; Sherman, 2000; Cortés, 2003; Pressman, 2005; Lutgendorf, 2005; Frick, 2005; Von Ah, 2007). The CPAS has shown significant correlations with well known psychological (Holmes and Rahe Stress Scale and Beck Inventory of Depression) and immunological tests

(Flow cytometry for CD4+ lymphocytes). This research validated the English version of CPAS test (a detailed analysis is conducted in Chapter Three). The questionnaire has been designed to be used specially with PLWHA and consists of three demographic questions plus 16 questions divided into three sections:

HADS: Hospital Anxiety and Depression Scale. This scale has multiple benefits: it is short, easy to apply and has been used in many health studies with consistent and significant results on measuring anxiety and depression (Herrman, 1996; Bjelland, 2002 and Herrero, 2003). In addition, it measures two constructs at the same time: anxiety and depression. This scale consists of 14 forced choice Likert items. This test was translated into Spanish by the researcher and checked by Ana María Pizarro (Spanish language teacher, School of Modern Languages and Cultures, Faculty of Arts, University of Nottingham).

FDC: The Functional Dimensions of Coping (Ferguson and Cox 1997) gives a profile of coping strategies and has been validated in the UK (Corr, 2004). This test gives a qualitative interpretation; helped by his PhD supervisors, the same researcher interpreted all the results. The FDC consists of three sections: the first question asks the participant to describe the most stressful event in the last three months (this can be extended to six months); the second section asks the participant to describe the behaviours he/she adopted to deal with the major stress described; the third section consists of 16 questions aimed at evaluating the described behaviours over a range from 0 to six. This test also was translated into Spanish using the same process used to translate the CPAS and HAD.

6.2.2. Immunological parameters

Chile provides free access to medical care, treatment, and immunological and virological assessment to all persons diagnosed HIV+ (as do the UK and Romania). Chile uses as laboratory techniques *flow cytometry* and the *Polymerase Chain Reaction* (PCR) AMPLICOR® standard or ultra sensible essay (the same techniques are used in the UK and Romania).

Flow cytometry: This blood test shows the percentage and absolute number of CD4+ lymphocytes; it is the 'gold standard' technique for immune system cell counting, used worldwide to establish the impact of HIV on immune function (Sepulveda, 1997).

Polymerase Chain Reaction (PCR): This blood test is also considered the 'gold standard' for quantifying the number of HIV in circulating blood (Viral Load Level: VLL) and is used worldwide to evaluate the evolution of the HIV infection (Sepulveda, 1997).

Highly Active Antiretroviral Therapy (HAART): So far, the most successful strategy for dealing with HIV infection; combined drugs, referred to as a "cocktail" are used. The HAART reduces, in most cases, the HIV viral levels such that they become undetectable by PCR; it does not, however, eliminate the virus from the body and only acts in peripheral blood circulation (Sepulveda, 1997).

6.2.3. Adaptations for research instruments

The adjustments for this study consisted of the translation into English of the CPAS and its validation for use in England; and the adaptation of the FDC score features. HADS and FDC were translated into Spanish.

6.2.3.1. The "Cuestionario Percepción del Apoyo Social" (CPAS) validation.

The original Spanish version was translated into English and piloted in a sample of students from one department of the University of Nottingham. A preliminary version of this questionnaire was developed. This version was applied to a different sample of students from the same department and further changes were made. The final step in the validation process was the application using students from the University of Nottingham in general. A sample of 275 students was assessed on this evaluation obtaining the final English version. See Chapter Three for full details.

6.2.3.2. Scoring strategy for the FDC

The FDC scale offers 16 statements, each one with a scale ranging from 0 to six which participants use to evaluate their way of dealing with previously identified stressful events, determining the usage of four different copping strategies where 0 signifies no usage of that coping strategy and six means its full usage. Each coping strategy has a range from three to five items for each coping strategy (Table 6.2). This research proposes to obtain a mean score for each coping strategy following the same proposed interpretation, where the range "0" to "6" indicates the range of use of the specified strategy from low to high. This permits the comparison of different evaluations among the same participants and between different participants.

Table 6.2: items for Coping Strategy at FDC Scale

Coping Strategy	Item in the test
Approach	1, 7, 10 and 14
Avoidance	5, 8, 11 and 13
Emotional regulation	3, 6 and 9
Reappraisal	2, 4, 12, 15 and 16

6.3. Data collection and analysis

Data collection consisted of repeated psychological assessments and collection of clinical data from March 2008 until April 2009. Psychological variables were assessed every three months (evaluations in April, July, October 2008 and January and April 2009). Clinical data were obtained from the participants or from medical records. The distributions in the first and second evaluations were analysed for normality. A Wilcoxon test was used to compare psychological data from the first and second evaluations; other evaluation points were not included due to the reduced sample size. For the analysis, and based on the standardised agreement, a $p<0.05$ was considered significant. However, and following the analysis performed by Dancey (2007), this limit it is considered only as a reference rather than an absolute cut off, and when possible the exact p is informed. Spearman was calculated to analyse the relationship between psychological and immunological variables. Power and sample size effects were calculated.

6.4. Results

In this section, data from psychological and immunological evaluations are presented and analysed. Due to the small number of participants from the second evaluation on, the analyses only include the first and the second evaluation points. The first evaluation had a normal distribution; the second, however, was not normally distributed. Therefore, all analysis comparing the evaluations used non-parametric tests.

6.4.1. Demographic summary

The most notable features were the categories of female and married participants, both with just one participant. Based on the premise that the

perception of any phenomena is one of the most important factors determining individuals' behaviour in response to it, the question about income was posed in terms of how individuals perceive their income's adequacy regarding their specific needs.

Table 6.3: Chile, first evaluation of PLWHA: Demographic data

Variable		% of N 24
Sex	Male	96%
	Female	4%
Age	Mean (SD = 9.21)	36.92 years
Educational level	Secondary	52%
	Higher	48%
Living with [or 'Household']	Alone	28%
	Parents	24%
	Friends	24%
	Couple	24%
Marital status	Single	76%
	Married	4%
	Cohabiting	20%
Your income is?	More than adequate for your needs	0%
	Adequate for your needs	44%
	Less than adequate for your needs	56%
Diagnosis	N of years until 2008	6.84 years

6.4.2. Analysis of psychological data

In this section the results of the psychological evaluations conducted for the first and the second evaluations of Chilean participants are presented and analysed.

6.4.2.1. Perceived social support (CPAS)

CPAS scores in the first (median: 54; range: 44; n: 24) and second (median: 59; range; 18; n: 9) evaluations showed no differences (Wilcoxon t=12; z = .842; p>0.05). Despite the great reduction in the sample for the second evaluation only a moderate sample size effect was

found (means: 53.43 and 57.11; SD 9.47 and 6.5 respectively for the first and second evaluations; d= 0.458).

CPAS Section Two explores quantitative referents for social networks. PLWHA in Chile reported being members of three to four networks; friends, work, family and partners were most commonly mentioned in both evaluations. Friends (35.2%), family (17.6%) and partners (13.04%) were reported as the most emotionally close or supportive for the first evaluation. Partners and friends obtained 33.3% each and family 11% in the second. In terms of how often participants communicate with their closest friends, weekly (82.6%) and monthly (13.04%) were the most common answers in the first evaluation, weekly obtained 88.8% and monthly 11.1% in the second evaluation.

6.4.2.2. Anxiety and depression (HADS)

The HADS gives a general score for both anxiety and depression. No differences were observed in anxiety medians of the first (six, range 18) and the second (six, range 17) evaluations.

Figure 6.1 shows that a reduction in depression median scores occurred in Chilean participants between the first and the second evaluation; this may indicate fewer symptoms or signs of depression detected by the test. However, no differences were observed using a Wilcoxon test (z= -.210, p> 0.05). The observed median difference is more likely to be related to the reduction in the number of participants in the second evaluation (63% less, 14 participants), and not necessarily to a decline in depressive symptoms in the Chilean participants. In fact, when the calculation included only the participants answering both evaluation points, the

median for the first and second evaluations obtained had the same value: four.

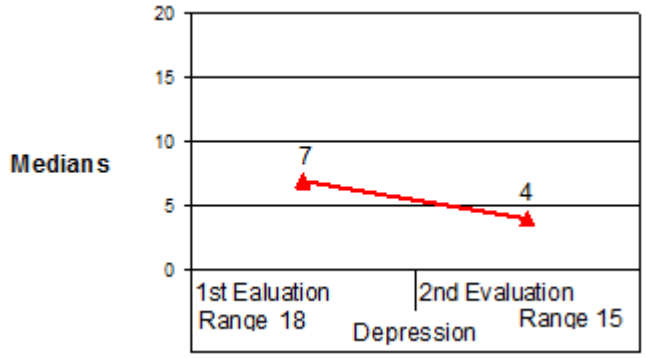


Figure 6.1: Chile, first & second Ev of PLWHA : HADS Depression medians

A post-hoc test (Tukey HSD) confirmed that the absence of differences between the two evaluation points for anxiety and depression (size effects: anxiety d = 0.039; depression d = 0.154) were unlikely to be due to sampling error.

These findings are in agreement with the general diagnosis given by the test. The HADS diagnoses of anxiety and/or depression were similar in both evaluations. For instance, less than a third of the participants studied scored higher than the limit defined by this test as *definite anxiety* or *depression* and more than 50% were evaluated as *unlikely* to have clinical *anxiety* or *depression*. See details in Table 6.4.

Table 6.4: Chile, first & second Ev of PLWHA: HADS diagnosis

	First Evaluation		Second Evaluation	
Diagnosis	**Anxiety**	**Depression**	**Anxiety**	**Depression**
Definite	25%	16.60%	22.22%	22.22%
Unlikely	54.16%	54.16%	66.7%	77.8%

6.4.2.3. Coping strategies (FDC)

The Functional Dimensions of Coping (FDC) gives a score related to the use of *Approach*, *avoidance*, *emotional regulation* and *reappraisal* as coping

strategies. The means of the scores arrived at in each of the items associated with each coping strategy were calculated; in this way a score from 0 to six was derived for each strategy and used for all calculations in this study.

Table 6.5 presents the medians, ranges, p-values for the Wilcoxon test and size effects (*d*) for both evaluations. At the first evaluation participants showed a tendency to use a direct approach to problems, with lower avoidance, good regulation of emotions caused by stressful situations and learning from experiences. For the second evaluation the median scores showed less use of approach, avoidance and emotional regulation. Nevertheless, none of the variations were of significant levels and except for avoidance the size effect was small for all coping strategies.

Table 6.5: Chile, Media (Range) of PLWHA: FDC scores

	First Eval (N: 23)	**Second Ev (N:9)**	**p value (Wilcoxon)**	**Size effect (*d*)**
Approach	4.5 (6)	3.5 (5)	Z= -0.847; p= 0.397	0.010
Avoidance	2.75 (5.5)	2 (3.75)	Z= -0.676; p= 0.499	0.580
Emotional Regulation	4.3 (6)	3.76 (6)	Z= -0.421; p= 0.674	0.126
Reappraisal	4 (6)	4.2 (4.6)	Z= -0.105; p= 0.916	0.145

The drop shown in avoidance scores may be raised by sampling error (d = 0.580) or could indicate lowered use of avoidance among those more adherent participants. Table 6.6 shows each coping strategy correlated with each other, in a comparison of the first and second evaluations. Highly significant correlations were found between almost all FDC coping strategies; the exception was the results of *avoidance*. This coping strategy had either no significant correlation (marked in grey) or correlations in the opposite direction to the one expected (bold lettering). Take, for instance, the correlation between approach and avoidance (r: 0.655) obtained in the

first evaluation. This may indicate the use of indirect approaches, such as not thinking about the problem or praying for help, as ways to deal with stressful situations. Similar results were found with regard to emotional regulation (r: 0.696) and reappraisal (r: 0.638).

Table 6.6: FDC variables correlation: first and second evaluations

	Evaluation	
Variables	**First (N:23)**	**Second (N:9)**
Approach/Avoidance	**.655****	-0.246
Approach/Emotional Regulation	.853**	.827**
Approach/Reappraisal	.871**	.941**
Avoidance/Emotional Regulation	**.696****	**0.04**
Avoidance/Reappraisal	**.638****	**0.092**
Reappraisal/Emotional Regulation	.709**	.912**

**: p< 0.01

The high levels of approach and avoidance among the same sample may indicate a need for understanding approach strategies in a more open way. Approach may not necessarily mean direct approach in terms of taking action and dealing directly with the situation. As mentioned, "approach" may include different, indirect ways to "deal" with problems and to avoid facing them directly, like praying or delegating responsibilities.

6.4.3. Immunological data

Data related to immunological status are reported, including: CD4+ lymphocytes, VLL and HAART. Table 6.7 shows descriptive statistics for the first and second evaluation of CD4+ counts. No significant differences were found; Wilcoxon test (z= -1.172, p> 0.05).

Table 6.7: Chile first & second Evaluation of PLWHA: CD4+ Descriptive statistics

Evaluation	N	Mean	Std. Deviation
First	24	431.8333	277.29
Second	9	494.6364	338.43

In terms of VLL, only two participants in the first evaluation and one in the second evaluation had counts above the detection limit (>50 virus/m³). PLWHA taking HAART usually have viral counts below the detection limit (<50/ml³ in blood). All the studied cases with VLL over the detection limit correspond to recently diagnosed participants, *naïve*[8] for HAART; therefore, their counts are extremely high (mean 70681.82) when compared to participants in HAART (<50). The same reason explains the 80% rate for participants in HAART. Chile has 100% HAART coverage.

6.4.4. Psycho-immunological correlations

This section explains the interactions between the psychological, immunological and demographic data reported in the previous sections. Analyses of these data provide a deeper understanding of the role played by these variables on PLWHA. The correlations between all psychological and immunological variables within the first (Table 6.8) and the second (Table 6.9) evaluations are described and correlations between these evaluations are analysed at the end of this section.

6.4.4.1. First evaluation

Contrary to the relationship commonly reported in the literature; PSS did not show significant correlations with other psychological nor with immunological variables during the first evaluation in Chile; see Table 6.8. However, analysing the CPAS sub-variables (self-development, esteem and belonging), a significant and negative correlation was found between

[8] This term refers patients who have never been under HAART.

belonging and anxiety (-0.52; p<0.05, n22) as well as a positive correlation between belonging and reappraisal (0.44; p<0.05, n22). Additionally, a negative correlation was found between esteem and depression (-0.42) with a p-value of 0.053.

These contradictory results may be explained by the low power (1-β= 0.426) of the test considering a medium size effect, α 0.05 and n=23. In this way the there were 57.4% chances to fail to find an existing effect. Anxiety and depression showed strong correlations with practically all the variables evaluated (and across every evaluation). With the exception of avoidance, similar results were seen with the FDC variables (reappraisal, approach and emotional regulation) and with the CPAS sub-variable of belonging (-0.505, p<0.05). Contrary to the studied literature, no significant correlations were found with CD4+ counts; however, this result may be related to the power limitation of this evaluation.

Table 6.8: Chile - First evaluation of PLWHA: Variable Correlations

Variables	CD4+	CPAS	Anxiety	Depression
Approach	0.183	0.103	**-.750****	**-.681****
N	22	22	22	22
Avoidance	0.13	0.243	**-.621****	**-.626****
N	22	22	22	22
Emotional regulation	0.11	0.024	**-.740****	**-.682****
N	22	22	22	22
Reappraisal	0.291	0.03	**-.697****	**-.498***
N	22	22	22	22
CD4+		-0.078	-0.305	-0.234
N		22	22	22
CPAS			-0.071	-0.184
N			22	22
Anxiety				**.685****
N				23

*: p< 0.05**: p< 0.01

In addition to the significant correlations described with HADS, the results of the FDC sub-variable avoidance were almost all opposite of what was

expected (as corroborated by Wilcoxon test). For instance, one result that contradicted expectations was the finding of a significant and negative correlation between the use of *avoidance* and anxiety (r: -0.621, n: 22; z= -3.338, p< 0.01). Similar results were found with depression (r: 0.626, n: 22; z= -2.711, p< 0.01). These may be related, as mentioned, to the use of avoidance as a strategy for 'approaching' stressful situations. In this way, avoiding stressors may temporarily reduce levels of anxiety and depression. The immunological variable (CD4+) did not have any significant correlation with other variables during the first evaluation point.

6.4.4.2. Second evaluation

No significant correlations were found between PSS and psychological or immunological variables during the second evaluation in Chile. However, the power of the evaluation was reduced to 0.21. Therefore, these results need to be carefully interpreted, especially because other results of this research and within the extant literature report positive correlations between social support and immune variables.

Table 6.9: Chile - Second evaluation of PLWHA: Variable Correlations

Variables	CD4+	CPAS	Anxiety	Depression
Approach	0.241	-0.249	**-0.456**	**-0.597**
N	8[a]	9[a]	9	9
Avoidance	**-0.398**	0.356	0.046	0.22
N	8[a]	9[a]	9	9
Emotional regulation	-0.024	-0.316	**-0.651**	**-0.565**
N	8[a]	9[a]	9	9
Reappraisal	0.19	-0.4	**-0.552**	**-.689**[*]
N	8[a]	9[a]	9	9
CD4+		**-0.639**	-0.156	-0.311
N		8[a]	8[a]	8[a]
CPAS			0.235	0.318
N			9[a]	9[a]
Anxiety				**.764**[*]
N				9

* : p< 0.05 **: p< 0.01

[a]: Data from next CD4+ evaluation were included in this correlation.

Anxiety and depression showed significant correlations with one another. Significant and negative correlations were found between anxiety and reappraisal. During the second evaluation a significant participant drop-out occurred (more than 60% of the participants did not reply at the second electronic evaluation).

Correlations between the scores of each variable comparing first and second evaluation (Table 6.10) show highly significant positive correlations for emotional regulation and the CD4+ count. This can be interpreted as a sign of stability, where lower (or higher) results in the first evaluation may predict similar scores in the second evaluation. No generalisations are attempted due to sample size.

Table 6.10: Chile - First and second evaluations - Variable Correlation

Variables	Variable Correlation	N
PSS	-0.18	8
Anxiety	**0.627**	8
Depression	**0.602**	8
Approach	**0.633**	8
Avoidance	**-0.436**	8
Emotional Regulation	**.903****	8
Reappraisal	**0.675**	8
CD4+	**.945****	11a

* : p< 0.05 **: p< 0.01

6.4.4.3. Correlations of demographic data

Tables 6.11a and 6.11b describe correlations between demographic psychological and immunological variables. *Educational level* had an inverse correlation with levels of anxiety (r: -.728, p< 0.05, n: 9) and with the use of emotional regulation as coping strategy (r: -.728, p< 0.05, n: 9). Remarkable correlations were found also between the *educational level*

and depression (r: -.522, p=0.1) and with approach (r: .522, p=0.1), all in the second evaluation.

Participants were asked about *marital status* and who they *lived with* as separate questions (Table 6.11a). Scores for correspondent answers were given as follows: one for living alone and 2 for any answer involving living with someone else (parents, friends or couple). For *marital status*: Single, cohabitant and married were assigned numbers one to three respectively. In this way the correlations are interpreted as follows: for instance, an inverse correlation was obtained for anxiety and *live with* someone (r: -.788, p< 0.05, n: 9; the Wilcoxon test give z= -2.431, p< 0.05). This shows a higher likelihood of finding elevated levels of anxiety in participants living alone compared with those living with someone else.

Table 6.11a: Chile - Psycho-Immune-Demographic correlations

Variable	Educ. Level		Live with		Marital situation	
	1st Eval	2nd Eval	1st Eval	2nd Eval	1st Eval	2nd Eval
Age	-0.067	-0.211	-0.1	-0.059	-0.032	**0.37**
N	24	9	25	9	25	9
CPAS	**0.347**	-0.106	**0.362**	0.122	0.271	0.053
N	22	9	23	9	23	9
Anxiety	-0.324	**-.728***	-0.126	**-.788***	-0.33	**-0.572**
N	22	9	23	9	23	9
Depression	-0.108	**-0.522**	-0.219	**-0.586**	-0.196	**-0.365**
N	22	9	23	9	23	9
Approach	0.188	**0.522**	0.152	**0.505**	0.268	0.157
N	22	9	23	9	23	9
Avoidance	0.116	0.052	0.191	-0.246	0.124	-0.261
N	22	9	23	9	23	9
Emot Regul	**0.361**	**.728***	0.151	**0.61**	0.028	0.052
N	22	9	23	9	23	9
Reappraisal	0.159	**0.621**	0.118	**0.488**	0.29	0.104
N	22	9	23	9	23	9
CD4+	-0.181	0	0.054	-0.261	**0.399**	0.126
N	24	8	24	8	24	8

*: p< 0.05 **: p< 0.01

However, when *marital status* was analysed no significant correlation was found. This could indicate, in the case of psychological health, the importance of *living with* someone whether or not the relationship is marital. However, due to sample characteristics (only 20% of the participants declared themselves married or cohabitant) further studies are necessary before final conclusions are made.

Table 6.11b: Chile - Psycho-Immune-Demographic correlations (continuation)

Variable	Income level		Diagnosis date	
	1st Eval	2nd Eval	1st Eval	2nd Eval
Age	-.051	**-.708***	**.845****	**.671***
N	25	9	25	9
CPAS	.325	-.265	.086	-.098
N	23	9	23	9
Anxiety	**-.398**	-.261	-.075	**-.441**
N	23	9	23	9
Depression	**-.584****	-.306	-.031	**-.570**
N	23	9	23	9
Approach	.330	**.830****	-.152	-.080
N	23	9	23	9
Avoidance	.283	-.044	.106	-.173
N	23	9	23	9
Emot Regul	.329	**.870****	-.135	-.214
N	23	9	23	9
Reappraisal	.257	**.866****	.184	-.025
N	23	9	23	9
CD4+	-.012	-.109	.325	.311
N	24	8	24	8

*: p< 0.05 **: p< 0.01

Income satisfaction was determined by the question "To what extent is your salary adequate for covering your living needs?", in answer to which participants could rate their income as less than adequate, adequate or more than adequate, with scores of one to three respectively assigned. It was found that *income satisfaction* was significant and correlated negatively with depression (-0.584, p<0.01; z= -3.6378, p< 0.01) and with age (-7.08; z= -2.670, p< 0.01). *Income satisfaction* was significant

and positively correlated with the use of approach (0.83; z= -2.552, p< 0.01), emotional regulation (0.87; z= -2.549, p< 0.01) and reappraisal (0.866; z= -2.524, p< 0.01) as coping strategies.

6.5. Conclusions

When compared with the students included in the CPAS validation (described in Chapter Three), PLWHA participants of this study obtained lower scores in PSS. In terms of anxiety and depression approx 25% of the participants reported suffering from these clinical conditions; this is considerably high compared to the 4.9 to 10.7% of the Chilean population (MINSAL, 2006) -and 7 to 11% of the UK population (Singleton, 2000). Approach, emotional regulation and reappraisal showed significant correlations with anxiety and depression. Additionally, avoidance was correlated with higher incidence of approach and lower incidence of anxiety and depression; these unexpected results, observed in the case of avoidance, were not influenced by participants' dropout rate at the second evaluation.

Significant correlations were established between anxiety, depression, approach, avoidance, emotional regulation and reappraisal. Negative correlations were found between *educational level*, *income satisfaction* and *live with* (whether the person lives alone or with someone) when correlated with anxiety and depression. Positively, but not as highly, correlated were *educational level* and *income satisfaction* with *PSS*. Belonging (CPAS sub-variable) was negatively correlated with anxiety and positively with reappraisal. In the same line, esteem (CPAS sub-variable) correlates negatively with depression.

The results of the evaluation of PLWHA in Chile gave partial response to the research question this chapter addresses: How are PSS, anxiety, depression, coping strategies (approach, avoidance, emotional regulation and reappraisal), CD4+ lymphocytes, VLL and HAART expressed and correlated in PLWHA from Chile?

The absence of significant correlations between PSS and anxiety, depression, coping strategies and CD4+ lymphocytes has been explained by the low power of the PSS evaluation and not necessary related with lack of relationship, which have been largely documented in the literature.

Based on the described data, no final conclusions can be made. This is mostly due to the reduced number of participants; however, the data points to the correlation between the studied psychological variables and to higher levels of depression and anxiety among PLWHA when compared with general population. There is enough evidence to support the relationship, established in the literature, between the studied psychological variables and to sustain the argument that the process of living with HIV/AIDS has strong psycho-social effects, transforming HIV/AIDS into a 'special' health condition due to the psychological impacts on people living with the virus.

Specific actions (individual meetings to explain details of the study) carried out during the recruitment process were addressed to improving participants' adherence. However, adherence in terms of response to the successive evaluations was an important issue during the evaluation process. Due to the location of the sample (Santiago, Chile) contact after the first face-to-face meeting was agreed to be via e-mail. Unfortunately, no alternative means of communication was created. This points to a difficulty for this strategy when, due to distance, e-mail evaluations are the

best cost-benefit strategy and are defined as the only way for future contact with participants. Future research using this strategy may evaluate the possibility of including alternative ways of contact, such as mobile or landline numbers, in case contact with a participant diminishes. In this case participant's informed consent sheet must include the possibility of phone contact when e-mail fails.

Next chapter (Seven) aims to pilot the Psychosocial Intervention Programme. Through this pilot application with PLWHA in England members of PSO a better understanding of the intervention itself and of the possible issues that an intervention of these characteristics may involve is expected. Additionally, Chapter Seven introduces the analyses PSO effects on PLWHA and Chapter Eight begins the analysis of the effectiveness of this Psychological Intervention Programme.

Chapter Seven: Psychosocial Intervention Programme – Pilot application

The objective of this pilot application of the Intervention Programme is to adapt and refine the new English version of this programme. Based on evidence supporting the influence of psychological interventions on the physiological functioning of PLWHA (Byrnes, 1998; Donaldson, 2000; Tomakowsky, 2001; Antoni, 2002; McCain, 2003; Antoni, 2005; Funck-Brentano, 2005; Kumakech, 2009); the Psychosocial Intervention Programme (Cortes, 2003) was adapted and piloted to be used among British participants. The aim of this intervention is to modify both psychological (perceived social support [PSS], anxiety and depression) and immunological variables (CD4+ lymphocytes) in order to improve PLWHAs' health statuses.

The Intervention Programme was originally developed in Chile (Cortes, 2003) to help PLWHA deal with depression and anxiety and to improve PSS. As a model for the Intervention, a programme implemented by the Health Ministry of Chile to deal with depression (Araya, 2002) was used. The English version of the Intervention Programme was developed which included the same variables and number of sessions as the original Chilean version plus the transversal use of coping strategies. As in the previous version, PSS was considered to be the key variable.

To adjust and test the English version of the Intervention Programme, a pilot application was launched, with the following aims:

- To acquire experience in the application of the intervention itself.
- To adapt the intervention to British participants.

- To adjust the intervention according its results.
- To detect weak points in methods or techniques used in the intervention.
- To optimise time and resources used in the intervention.

Participants were trained (by the author) to improve their social support and, based on this, to deal with stressful situations and to face depressive symptoms. Psychological and immunological parameters were assessed before and after the Pilot Intervention Programme. A baseline evaluation was the first step, and then the Intervention Programme, followed by a new psychological and immunological assessment, was conducted.

By including members of PSO, this study complements the analyses, begun in Chapter Six, of psychological, social and immunological variables of PLWHA. Data, such as the amount of time spent as a member of the group, were collected and compared with psychological and immunological variables in order to explore the possible health effects of membership in a PSO.

With this pilot application, the Intervention Programme was adapted for use with British population. Beyond its pilot purposes, this application gave extra information related to the following research questions:

1. How are PSS, anxiety, depression, approach, avoidance, emotional regulation and reappraisal, CD4+ lymphocytes, VLL and HAART expressed and correlated in PLWHA from England?
2. Are there immunological and/or psychological differences relating to the length of membership of PSO of PLWHA?
3. Will an intervention based on the improvement of PSS and the reduction of anxiety and depression influence immune system functioning of PLWHA?

These questions will be the aim of a full implementation of the Intervention Programme; however, preliminary analyses were performed using data taken from this pilot experience and are exposed as extra results.

7.1. Participants and methods

This study focuses on the pilot application aiming at the adjustment of the Intervention Programme. The pilot application used a quasi-experimental design which included a baseline evaluation, an Intervention Programme, and a post-intervention assessment. For ethical reasons, as well as by agreement with the manager of the peer support organisation (PSO) of PLWHA, each participant had the choice of being part of either the control group (which only included two psychological evaluation points) or the experimental group (which received assessments and the Intervention Programme). Therefore, randomisation was not performed to either the control or the experimental group.

As with the original Spanish version, the programme consisted of 13 sessions, modelled on an original programme implemented by the Health Ministry of Chile to deal with depression (Araya, 2002) which was executed over five sessions (considered sufficient to start the process of changes aimed at by the intervention). In this way, a total of 13 sessions were defined for the programme: five sessions were retained for the depression programme, four sessions were consigned to the Anxiety programme and four to the Perceived social support programme. The information and techniques taught were highly interconnected, and coping strategies were included transversally throughout the programme.

7.1.1. Participants

Definition of the population: PLWHA members of PSO in the UK. Men and women between 18 and 60 years, diagnosed as HIV+ by the National Health System (NHS), before 31st April 2009. Participants were recruited from a PSO in the East Midlands. From a total of 24 possible eligible participants, 12 persons (seven men and five women) agreed to be part of the study. Four persons (three men and one woman) agreed to be allocated as the "control group" and 8 volunteers (two groups: four men and four women) were ready to start the Intervention Programme. Male participants were recruited during their regular Wednesday meetings; female participants' recruitment was carried out at their monthly meeting. Participants provided written informed consent (Appendix L) and received feedback for the evaluations undertaken.

Table 7.1: Inclusion – exclusion criteria for PLWHA

Inclusion	Exclusion
a) Men and women between 18 and 60 years old	a) To be seronegative for HIV
b) Diagnosed as HIV+ by the NHS before 31st April 2009	b) To be in the symptomatic stage of HIV evolution (AIDS) according to the CDC criteria (1993) and be unable to follow a group session intervention because of acute opportunistic diseases
c) Fluent in English	c) To be unable to provide informed consent.

Informed consent: It followed the same process as the described for the Psycho-immune assessment of PLWHA in Chile (Chapter Six, page 139). For details of the English version see Appendix L.

7.2. Materials and instruments

7.2.1. Psychosocial assessment

The same three instruments used for Chilean participants, as described in Chapter Six, Psycho-immune variables of PLWHA (p. 140-42), were used for this pilot study. These instruments were the Questionnaire of Perceived Social Support (CPAS), the Hospital Anxiety and Depression Scale (HADS) and the Functional Dimensions of Coping (FDC) Scale. Additionally, a demographic data collection survey was applied.

7.2.2. Clinical data

As in Chapter Six - Psycho-immune variables of PLWHA (p. 140-42), clinical data consisted of the CD4+ lymphocyte count, assessed by flow cytometry; the HIV viral load level (VLL) assessed by the Polymerase Chain Reaction technique (PCR) and the intake of highly active antiretroviral therapy (HAART).

7.2.3. Procedure

The Intervention Programme started with a baseline evaluation of psychological: PSS, anxiety, depression and coping strategies; clinical: CD4+ lymphocytes, VLL and the intake of HAART; and demographic data. Following this assessment the Intervention Programme began. The second psychological assessment and clinical data collection was carried out at the end of the last session of the Intervention Programme.

7.2.4. Psychosocial Intervention Programme

This Intervention Programme was fully implemented by the author of this PhD research project and consisted of sessions of 60 or 90 minutes once a

week divided into three sections. Group modality was used, since it is maintained that it is within a group -in relationships- where the skills related to social networking can be acquired. The context around the individual can strongly affect the perception of the support received by each member of the group (Zagenczyk, 2010). Similarly, studies have shown that intervention targeting depressive symptoms, physical activity and coping strategies can improve quality of life of PLWHA (Kowal. 2008). Therefore, by providing participants with information and techniques to improve their utilisation of the support provided by their networks and their coping strategies, this Intervention Programme aims to develop in the participants an easier approach to their available social network of support; the training and utilisation of techniques for dealing with stressful situations and depression; and the achievement of better utilisation of coping strategies. By modifying psychological parameters, the Intervention Programme pursued immunological improvements represented by the increase in the number of CD4+ lymphocytes. Therefore, positive psychosocial interactions are considered to be factors optimising psycho-biological balance. Table 7.2 summarises the structure, variables and techniques included in the Intervention Programme.

As mentioned, the Intervention Programme was divided into three sections. All three sections included an initial informative sub-section. The purpose of this was to familiarise the participant with and coordinate the language to be used for the specific section. These sub- sections provided the participant with useful information as he or she began to redefine his or her approach to the specific variable. The second sub-section of all three sections connected the new information with personal life experiences, translating clinical definitions into quotidian examples in order to see the real dimension of possible symptoms and to achieve a better understanding

of them. This process also helped participants to realise and interpret their organic, psychological and social reactions and used adaptive rather than maladaptive responses. The last sub-section of each section included different techniques for the reduction of anxiety and depression symptoms, and strategies for solving conflicts and improving social interactions. These included, among others, breathing, relaxation, imagery, visualisation, conflict management, panel discussions, feedback and group activities. For details of the intervention see Appendix M.

Table 7.2: Psychosocial Intervention Programme: Contents

Meeting	Topics	Strategies
First meeting	Presentation First Assessment	 Psychosocial Assessment
Section One: Depression Session 1 to 5	Depression: Basic information Understanding depression Treatment	How to identify Conflicts Strategies for conflictsolution
Section Two: Anxiety-Stress Session 6 to 9	Anxiety: Basic information. What causes stress and anxiety Treatments	Relaxation - Breathing Visualisation Imagery
Section Three: PSS Session 10 to 13	PSS: Basic Information How PSS works? Groups and identity	Confidence play Discussion Feedback
Final meeting	Second Assessment Farewell	Psychosocial Assessment

7.2.5. Data analysis

This quasi-experimental pilot application had experimental and control groups. Distributions were analysed for normality.

Adaptations, modifications and additions to the English version of the Intervention Programme were based on two main factors:

- Pre-intervention factors such as baseline psychological and immunological status, length of membership in the PSO and time under HAART; and
- Intervention factors such as verbalisations related to the intervention process and attendance/withdrawal relationship.

An extra source of data, which might be called post-intervention factors (such as psychological and immunological status or verbalisation related to the intervention process), is summarised at the end, and is fully analysed in the next Chapter – Case Report. Data are presented, then analysed and finally conclusions are revealed.

Based on these premises, a Wilcoxon test was used to compare psychological data. A T-test was used to compare immunological data with the years of membership in the PSO. Spearman was calculated to analyse the relationship between psychological and immunological variables considering the number of sessions of the Intervention Programme they attended.

In the next section (Results), demographic, clinical and psychological data will be presented. In the Discussion section, these data will be analysed and discussed related to the impact they had on the development of the application of the Intervention Programme, highlighting learning processes and offering solutions for the encountered problems. Finally, in the Conclusions section the changes performed to the Intervention Programme will be presented. Additionally, and as an extra source of information, several statistic analyses were performed with the collected data, regarding the effectiveness of the Intervention Programme and the effects of PSO. Despite the fact that these analysis are outside of the scope of the pilot application, they contribute to the main target of this research: the understanding of the process of living with HIV/AIDS.

7.3. Results

This section details the main outcomes of this pilot in the two defined areas (Pre-intervention and intervention), comparing the experimental and control group with the goal of obtaining useful information for the modification of the pilot version of the Intervention programme.

7.3.1. Pre-intervention factors

This section provides the data related to demographics, baseline clinical and psychological data, length of membership in the PSO and under HAART.

7.3.1.1. Demographic summary

The overall mean age was 40 years (SD 8.12), the mean age of the experimental group was 41 years (SD 10) and of the control group, 40.5 years (SD 2,65).58.3% of the participants were men and 41.6% women. Participants predominantly mentioned the use of coffee and smoking habits. At the baseline assessment, seven (58.3%) considered their income to be less than adequate for their needs. One significant demographic difference, established by Kruskal Wallis test, was related to the length of membership in a PSO (medians: control 13.5 years; experimental-women 0.75 years; experimental-men 5 years; $x^2 = 6.102$, (2); $p = 0.047$). Nevertheless, when was compared to each other, this difference was only presented between women and control groups (Mann-Whitney $U = 1$; $z = -2.033$; $p = 0.057$). For detailed tables see Appendix N.1, N.2 and N.3.

7.3.1.2. Clinical data

In terms of clinical data, all participants with available viral load level (VLL) had an 'undetectable' count for the number of viruses in the circulating blood. As explained in Chapter One, this is a normal situation for people undergoing HAART. Except for two participants, every participant was receiving HAART, both of them in the experimental groups (a man and a woman). These participants were newly diagnosed and were in the initial stages of clinical analysis, as 100% of PLWHA in the UK are covered by HAART. The main clinical difference was the considerably higher CD4+ counts among the control group (median: 1010) compared to the experimental-women group (median: 420) and the experimental-men group (median: 520). The difference was established by the Kruskal Wallis test; $x^2 = 4.845$ (2); $p = 0.089$). Full tables are presented in Appendix O.

7.3.1.3. Psychological data

Table 7.3: UK, Baseline Evaluation of PLWHA members of PSO: Median scores

Groups	Control	Experimental groups		
Variable	Women and men: N: 4	Women and men: N: 8	Women N: 4	Men N: 4
Perceived support	51	42	51	37
Anxiety	6.5	9.5	9	11
Depression	4.5	5.5	3	9
Approach	3.5	3.875	3.125	4.125
Avoidance	3.5	1.875	3.125	1.375
Emotional regulation	3	4	3	4.335
Reappraisal	3.6	4	3.6	4.4

The psychological baseline evaluation (Table 7.3) shows higher scores in PSS and lower scores in anxiety and depression for the control group compared with the experimental groups. The women's group's general scores were higher than the men's group and similar to the control group.

In terms of coping strategies the control group had lower general scores for approach, emotional regulation and reappraisal, and higher scores for avoidance when compared to the scores of the experimental group. Men showed higher use of approach and reappraisal as coping strategies, and women of avoidance.

7.3.2. Intervention factors

This section relates to the implementation of the intervention. Variables related the level of attendance and to withdrawal, as well as the reasons participants decided to keep attending the intervention or to withdraw are discussed.

7.3.2.1. Adherence

The adherence to the Intervention Programme was one of the main issues to be dealt with; of the eight participants in the two experimental groups, two men began the programme during the third session. Two withdrew by the fifth session and the other two by the sixth. One woman withdrew by the third session and another by the sixth. Of the eight participants, only two women finished the Intervention Programme. One woman from the experimental group was not available for the second data collection at the end of the Intervention Programme. In this regard, a common comment from the participants who adhered to the Intervention was the difficulty of attending every week for such a long period of time.

A notable characteristic of the withdrawal-adherence rate was the significant correlations between baseline psychological variables (PSS: 0.988, $p<0.001$, n8; anxiety: -0.859, $p=0.006$, n8; and depression: -0.958, $p<0.001$, n8) and the number of attended sessions (Appendix P.1). Social support has previously been correlated with adherence to treatment

and attendance to health programmes, showing higher adherence among people receiving higher social support (Gardenier, 2010).

7.3.3. Post-intervention factors

Significant psychological and immunological improvements, sustained over a long period of time (two years) were described by one of the participants in the Intervention Programme. The next Chapter explains this case in detail and hypothesises about the importance of personality characteristics, such as belief and conviction, to the success of PNI-based interventions.

7.4. Discussion

This section evaluates the impact of pre-intervention participant characteristics on the intervention process and results; demographic data, baseline clinical and psychological data, length of membership in a PSO and time under HAART are included. Issues which occurred during the implementation of the Intervention are also analysed and discussed.

In terms of demographic and clinical data, participants who had spent more time as a member of the organisation or had a higher number of CD4+ lymphocytes were more likely to include themselves in the control group and not in the experimental group. These variables seem to predict the need of PLWHA to be offered activities such as those in the Intervention Programme when their CD4+ counts are lower. Newer members of peer-support organisations seem to be more prompt to take part on these programmes.

Compared with the students included in the CPAS validation (Chapter Three), PLWHA participants of this study obtained lower scores in PSS

(Medians: PLWHA 46 points; Students 55; Mann-Whitney U= 781; z= -3.04; p= 0.002), supporting the hypothesis of HIV/AIDS as a bio-psycho-social process with higher psycho-social impact as a result of stigma and discrimination against PLWHA. Psychological data indicate that individuals with higher psychological symptoms were more likely to take part in the experimental group in the Intervention Programme, these individuals also had lower CD4+ counts This result may indicate an extension of Crook's (2005) description of PLWHA seeking help from community-based AIDS services as being more vulnerable with higher loneliness and psychological symptoms, poorer reported health and, additionally, poorer immune functioning. Furthermore, that more vulnerable PLWHA are not only more likely to join one of these PSO groups, but are more active in the activities offered, such as the type of Intervention Programme. Another explanation may be that members whose membership is longer may have been exposed to more psychosocial help. These results indicate that participants with more (worse) psychological symptoms were more likely to take a more active role in the Intervention Programme; however, these participants also exhibited lower adherence to the programme.

Based on these results, commitment is established as an important factor related to adherence and, therefore, to the success of the Intervention Programme. Thirteen weeks with one weekly session each requires a substantive level of commitment from the participants and, if such a long intervention is planned, an accordingly encouraging pre-session strategy must be carried out. The second option is a shorter intervention which may ensure higher adherence, but may affect the effectiveness of the intervention. Special emphasis must be placed on the results of the baseline evaluation, and direct action should be taken to improve adherence among highly psychologically affected participants. These

actions may involve restructuring the activities so that the intervention emphasises the variable (anxiety, depression or PSS) first, which could have a stronger influence on participants reinforcing adherence.

Length of membership in an organisation of PLWHA seems to be related to the option of taking part—or not—in this kind of psychological interventions. As was mentioned, participants opting to take part in the experimental groups were, on average, "younger" in their organisational membership as compared to those opting to take part in the control group—the average difference between the experimental and control groups was more than 10 years of membership. This could indicate that people who were members of these institutions for a longer period have less interest in taking part in these kinds of interventions. However, it could also be related to wellbeing, or the perception thereof, indicating better psychological status, and therefore less need for psychological interventions. Additionally, participants scoring higher for PSS and lower for anxiety and depression at the baseline, attended a greater number of sessions during the Intervention Programme.

7.5. Extra analysis – Beyond the pilot application

As a way to achieve a better understanding of the collected data and to answer the specified research questions; Spearman correlations were computed to compare psychological, demographic and immune variables. In terms of psychological variables, highly significant correlations were found at the two evaluation points. Full correlations tables are presented in Appendix Q.1 (baseline) and Appendix Q.2 (second evaluation).

CPAS: At the baseline, PSS had high negative correlations with anxiety (-0.887, p<0.001, n12) and depression (-0.94, p<0.001, n12); similar negative correlations with HADS subscales were found in the second evaluation (anxiety: -0.861, p= 0.001, n11; and depression: -0.961, p<0.001, n11), additionally, a positive correlation was found with the use of approach as a coping strategy (0.69, p=0.019, n11).

HADS: In the baseline evaluation, anxiety correlated positively with depression (0.835, p=0.001, n12); in the second evaluation this correlation was higher (0.918, p<0.001, n11). Additionally, anxiety correlated negatively with approach (-0.858, p=0.001, n11) and emotional regulation (-0.65, p=0.03, n11) and depression was negatively correlated to the use of approach as a coping strategy (-0.781, p=0.005, n11).

FDC: At baseline, approach had highly positive correlations with emotional regulation (0.93, p<0.001, n12) and reappraisal (0.838, p=0.001, n12) and emotional regulation with reappraisal (0.878, p<0.001, n11). Similar results were found in the second evaluation: positive correlations of approach with emotional regulation (0.707, p=0.015, n11) and reappraisal (0.675, p=0.023, n11); and between emotional regulation and reappraisal (0.743, p=0.009, n11).

The CD4+ counts had a significant correlation with the years spent as a member of the PSO (0.813, p=0.004, n10). Age was positively correlated with approach (0.648, p=0.031, n11), emotional regulation (0.725, p=0.012, n11) and reappraisal (0.82, p=0.002, n11); (Appendix R.1).

The number of attended sessions was correlated with research variables as a reference point for the impact of the intervention. These correlations

were maintained for the second evaluation (Appendix P.2): PSS: 0.954, p=0.001, n7; anxiety: -0.891, p=0.007, n7; and depression: -0.946, p=0.001, n7. These data may be a reference point for the positive impact of the intervention; however, they may also refer to the higher adherence of participants with lower psychological symptoms. New applications of the intervention programme are required for conclusive hypothesis in this regard.

It was found that length of membership is related to immunological status (0.813, p=0.004, n10), the media for length of membership in PSO was 4.5 years (range: 0.5 – 19 years). In order to study the influence of this membership, participants' data were allocated into two groups: above and below the media of membership. Table 7.4 present the media scores for each group: 'Oldest' members of the PSO had a median of 950 CD4+ lymphocytes (the normal range is 800-1200); among 'younger' members, however, the median was 450 (classified by the CDC as immunosuppression). Regarding psychosocial variables: at baseline the results were similar: higher scores for oldest members in PSS; lower scores in anxiety and depression; higher scores for approach, emotional regulation and reappraisal and lower avoidance as coping strategies.

Table 7.4: UK: Baseline evaluation of PLWHA - Media scores above or below the media of years of PSO membership

Media of years in PSO: 4,5	Media of variable above Media of year	Media of variable below Media of year
PSS	50	37
Anxiety	6.5	14.5
Depression	3.5	11
Approach	4	3
Avoidance	2.25	3.375
Emotional Regulation	4	3
Reappraisal	4	3.5
CD4+	950	450

Possible alternative explanations for these findings may be:

a. As a secondary effect of the use of HAART: People living with the virus for a longer period may have started HAART earlier, increasing their chances for higher CD4+ counts.
b. People living longer with the virus may have learned how to deal with their situation, due to experience acquired over time.

However;

a) The length of time a patient spent on HAART was neither related to the CD4+ count (r: -0.265, p=0.458, n10; Mann-Whitney U= 7; z= -7.98; p= 0.425) nor to the time of membership in the PSO (r: -0.120, p=0.725, n10; Mann-Whitney U= 10; z= -4.11; p= 0.681). See details in Appendices 13a and 13b. This may indicate that the correlation between being a member of a PSO and the number of CD4+ lymphocytes in circulating blood in the participants of this study is independent of the time that participants have been in HAART. Therefore, and as suggested in Chapter Three and previously in this Chapter, a relationship between being a member of a PSO and immunological parameters is assumed. These correlations were corroborated using Mann-Whitney: U= 2; z= -2.19; p= 0.028. Nevertheless, once again, the condition of pilot application prevents the conjecture of any further hypothetical explanation. However, it is remarkable that effects between these variables have been found in this relatively small sample. Further, the study does provide a substantial amount of information to be considered in future applications of the Intervention Programme.

b) Regarding psychosocial variables, the simplest explanation is “the experience” itself. Living with HIV/AIDS, as with any other complex, stressful and life-endangering condition causes several physical and

psychological side effects with an enormous impact on the general well-being of individuals. However, dealing with these stressful events may impart knowledge and enrich each person's strategies for dealing with stressful conditions. This allows people to have different points of view about specific situations and, if the environment is 'propitious' it can provide the individual with useful coping strategies. Therefore, it is not surprising to find higher levels of PSS, lower levels of anxiety and depression and better emotional regulation among long term PLWHA as compared with people who have lived with the virus for a shorter time. In fact, these 'propitious environments' are proposed as the key factor, and PSO are proposed as a fundamental 'propitious environment' for PLWHA. Support for this explanation is provided by better PSS and lower anxiety and depression among PLWHA who have spent longer in PSO.

The time participants have received HAART also seems to have positive psychological effects. As for length of membership, the media for years under HAART was obtained, forming two groups (Table 7.5).

Table 7.5: UK: Baseline evaluation of PLWHA - Media scores above or below the media years of HAART intake

Media of years in HAART:	Media of variable above Media of HAART	Media of variable below Media of HAART
PSS	58	38
Anxiety	5	10
Depression	2	6
Approach	4	3.125
Avoidance	3.5	1.875
Emotional Regulation	4.67	3
Reappraisal	4.6	3.6
CD4+	950	510

Media scores for all variables were calculated. The Mann-Whitney test gives results at the threshold for the defined significance limit: for PSS in the baseline (U= 3.5; z= -1.74; p= 0.081) and in the second evaluation (U=

2.5; z= -1.83; p= 0.067); for anxiety at the baseline (U= 2.5; z= -1.95; p= 0.051); depression in the second evaluation (U= 2.5; z= -1.84; p= 0.067); and significantly for anxiety at the baseline (U= 0; z= -2.39; p= 0.017) and for approach in the second evaluation (U= 0.5; z= -2.31; p= 0.021). Full data are available in Appendix R.2. This may indicate positive side effects of HAART; this factor will be studied in future replications of this intervention.

The results of this study strongly suggest a positive response to the question of whether there are immunological and/or psychological differences relating to the length of membership of PSO of PLWHA. Participants who had spent longer time in PSO had better PSS; they displayed lower symptoms of depression and anxiety; they used more approach, emotional regulation and reappraisal and less avoidance to deal with conflictive situations; and they had more CD4+ lymphocytes in their immune system. However, they were less ready to take part in the experimental part of the programme. On the other hand, participants with better psychological and immunological results who decided to take part in the intervention had a higher rate of adherence to the programme in comparison to participants with poorer psychological and immunological results. These data can compound the predictive factors for future administrations of the Intervention Programme. Although no final conclusions are proposed, there seems to be a tendency for drops in psychosocial variables with lower adherence to the Intervention. People with poorer PSS might avoid situations that could in fact improve their levels of anxiety and depression or extend their social networks, and by this avoidance actually increase their symptoms. These data may give useful information for taking on these repetitive cycles among PLWHA.

7.6. Conclusions

The pilot application of the Intervention Programme involved a conscious process of learning about the implementation itself as well as about the characteristics of PLWHA in England. This implementation allowed the development of an English version of this Programme, improved thanks to the experience of its application and to dealing with different situations during the pilot implementation process.

Despite the considerable drop-out of participants, it was possible to carry out the intervention in full and gain valuable experience and understanding about the implementation process of the Intervention Programme. Additionally, useful data relating to the inclusion and adherence of participants to the programme was obtained.

Demographic data such as age, gender and use of HAART appear not to be related with the decision to take part in the Intervention Programme. On the contrary, psychological data appears to influence the decision of the participant to opt for the control or experimental group which may influence final results and comparison between the two groups. One possible solution is randomisation to either the control or the experimental group; however, this procedure is not always possible when working with volunteers. Another option would be the use of a quasi-experimental design. For this pilot application the latter was chosen.

As mentioned, a 13-session programme calls for a substantive level of commitment, a point which should be addressed during the process of recruitment of participants. This pilot application has made clear that for a successful implementation of the Intervention Programme, commitment

and length of the Intervention need to be balanced. To this purpose baseline evaluation, as a predictor for withdrawal, can give valuable information to increase adherence and ensure success on a full implementation of the Intervention Programme. Future administrations of this Intervention Programme might consider a smaller number of sessions to ensure higher adherence from participants; however, it should be taken into account that by offering different strategies to deal with anxiety caused by stress and depression, and by empowering participants in the use of social networks of support, this Intervention Programme aims to modify participants' perceptions of their environment and their psychobiological relationship to this environment; in view of this, a shorter intervention may not be as effective.

Taking into account this latest alternative, a shorter version of the intervention programme was outlined. Appendix S summarises the six-session Intervention Programme; however, new pilot applications to evaluate effectiveness in modifying both psychological and immunological variables need to be performed for this shorter version. Variables and techniques used in the 13-session Intervention Programmes are also used in the shorter version reducing the time expended giving theoretical information about social networks, anxiety and depression and focusing on practicing techniques to develop skills for dealing with these psychological variables.

One of the main contributions of this pilot study is the inclusion of an area of HIV/AIDS which has been little studied: Peer Support Organisations of PLWHA and the use of cooperative strategies for the self-provision of social support as a factor capable of influencing the immunological status of these groups' members. As mentioned, a positive relationship was found between

length of membership to PSO and immune functioning, and the effect was independent of the use of HAART. Additionally, the length of time participants have undergoing HAART was positively correlated with PSS and the use of approach and negatively with anxiety and depression. Similarly, Rabkin (2000) described distress reduction over a sample of PLWHA during the two first years HAART become widely available (1995-1997); however, no clinical improvements were reported in her sample. The psychological effects of HAART are beyond the scope of this study; however, to have found this effect in a relatively small sample of participants is a remarkable result.

A comparative experience is the next step for this research, studying psycho-immunological data between members and non members of PSO and between PLWHA and the HIV- (negative) population.

As described at the beginning of this Chapter, the aims for this Pilot Application were: to acquire experience in the application of the intervention itself; to adapt the intervention to British participants; to adjust the intervention according to its results; to detect weak points in methods or techniques used in the intervention; and to optimise time and resources used in the intervention. On the basis of these goals, it can be confirmed that the pilot application of the Intervention Programme achieved its purpose.

Chapter Eight - Case report

One of the most remarkable results of the pilot application of the Intervention Programme described in Chapter Seven was the significant and constant immunological improvement (increase of the number of CD4+ lymphocytes cells) observed in one of the participants (identified as DB[9]). Her results are described here and argue in favour of an improvement in her perception of social support (PSS); reductions in her anxiety and depression; and of her immune system functioning, based on a psychosocial intervention.

Direct correlations between psychological interventions and immunological improvements are commonly limited and difficult to establish. Normally, the number of cells in the immune system is stable and modifications (increases or reductions) require a minimum of three months of observation to establish a difference. This chapter describes the case of a participant in the pilot application of the Psychosocial Intervention Programme (described in Chapter Seven) who reported considerable and sustained increases in immunological parameters immediately after attending the Intervention Programme. This case report describes potential direct correlations between immunological improvements of a person living with HIV/AIDS and her participation in a Psychosocial Intervention Programme.

8.1. Case presentation

The case study was included in order to further explore the immunological improvements observed in one participant of the Pilot Intervention

[9] The ID code assigned to the participant has been modified for confidentiality reasons.

Programme. This participant attended all 13 sessions of the Intervention Programme and from the beginning of the programme showed a particular interest in the techniques used as well as belief in the relationship between psychological and immunological factors and in the benefits she could obtain based on these types of interventions. The participant had an excellent psychological response to the Intervention Programme and, once she had finished the intervention, the participant's immunological parameters (CD4+ lymphocyte count) started a significant, constant increase which was maintained over time. Because of this, a deeper analysis was performed.

8.2. Materials and instruments

In addition to the instruments used during the Intervention Programme (Perceived social support [CPAS], anxiety, depression [HADS] and coping strategies [FDC]), evaluated before and after the Intervention Programme, a case study protocol (Appendix T) and a semi-structured interview (Appendix U) were used to obtain and complement demographic data (Appendix V), past and present medical history, immunological records, social factors, general health status review and specific data related to the Intervention Programme. The CD4+ results were provided by DB who received a full report from the hospital where she is normally monitored.

8.2.1. Intervention

The three month Intervention Programme consisted of 13 sessions divided into three sections. (See details in Chapter Seven; p. 163-167). The intervention addressed the enhancement of immune functions by improving PSS, coping strategies and strategies for dealing with anxiety

and depression (Appendix M). DB attended all of the intervention sessions, receiving training on the described techniques.

8.2.2. Data collection

Psychological data and clinical information for the baseline and second evaluations were collected during the Intervention Programme (described in Chapter Seven). These included PSS, anxiety, depression, coping strategies, CD4+ lymphocytes count, VLL and HAART data. As a third evaluation point, further psychological, and clinical data (over the same variables) were collected a year and four months later. In addition, a case report protocol (Appendix T), and a semi-structured interview (Appendix U) completed the third evaluation. The long period between the second and third evaluations allowed for the obtaining of data regarding the influence of time on the characteristics evaluated. Data collection was carried out in the context of three in-person assessments. The first evaluation was in September 2007 (baseline pre-intervention assessment); the second in December 2007 (post-intervention assessment); a third evaluation was conducted in April 2009.

The remarkable improvement in DB's immune system, expressed by the significant and persistent increase in number of CD4+ Lymphocytes, is the origin of the researcher's decision to study this case in depth. Psychological and immunological results over the three evaluation points were compared and cross-referenced with immunological records. A thematic analysis was used to identify the participant's interpretations of and views regarding her immunological rise; these data were obtained from two semi-structured interviews. A pre-intervention/post-intervention comparison was carried out based on three psycho-immunological evaluations. The participant's

recall for the Intervention Programme content and her perception of the usefulness of the demonstrated techniques were also evaluated.

8.3. Patient profile

DB is a healthy, 34-year-old white British woman; she is a married mother of a girl of six, and has been living with HIV since 2001. She has had highly active antiretroviral therapy (HAART) since diagnosis.

8.3.1. Medical history

DB is under treatment for varicose veins, and has been in surgery. She suffers from hay fever and an allergy to grass, cat hair and dust. She consumes caffeine at levels that, according to FDA reports, could be harmful (FDA, 2005 and 2006); however, DB has generally healthy eating habits. DB had normal side effects from the HAART during the initials six weeks (weight increase and lack of energy), but these side effects did not persist for long.

8.4. Results

This section describes the results for the three psychological evaluations (September and December 2007 and April 2009) and the four (July and December 2007, December 2008 and July 2009) immunological data collections (Figures 8.1, 8.2, 8.3 and 8.4). DB's immunological tests are normally performed every six months.

8.4.1. Baseline assessment

DB's psychological evaluation pointed towards to a positive perception of the support received from social network; moderate levels of anxiety; no

signs of depression; and balanced use of all four assessed coping strategies, with a tendency to face problems directly and to learn from experiences. The 510 CD4+were normal for someone living with HIV under HAART; however 500 CD4+ indicates the limit for clinical immunodeficiency (red line in Figure 8.1).

8.4.2. Post-intervention assessments

The second evaluation indicated the highest CD4+ count since DB was diagnosed as living with HIV: 710cell/m³ (Figure 8.1). Her PSS was slightly higher in relation to the baseline evaluation (Figure 8.2). Anxiety showed an increase that put her slightly above the cut-off for self-reported anxiety (red line in Figure 8.3). DB reported that despite high levels of stress during the second evaluation period she was able to deal with her anxiety in a more proactive way. Depression remained in low scores with no significant variation. All coping strategies had higher scores (Figure 8.4). These scores point to higher reappraisal as a main strategy, followed by approach.

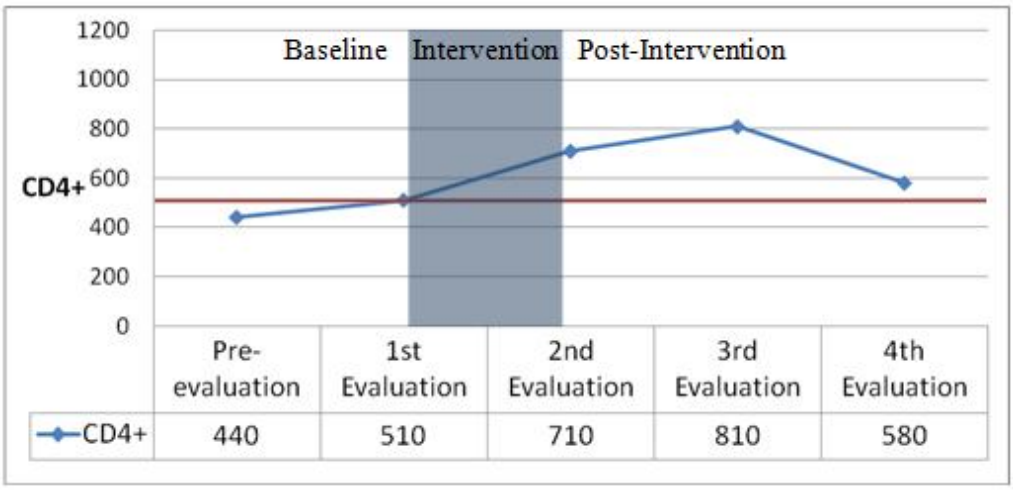


Figure 8.1: CD4+ pre, first, second, third and fourth evaluations

The third evaluation was carried out one year and four months after the second evaluation, and assessed the changes over the variables in a

substantive period of time. The CD4+ lymphocytes showed 810 cell/m³ (the latest available). Once again, these were the highest CD4+ counts DB had had since HIV diagnosis. Latter, data from a fourth CD4+ evaluation (July 2009) was obtained showing lower counts as compared with the third evaluation (Figure 8.1).

Social networks were perceived as highly supportive with similar scores to second evaluation (Figure 8.2).

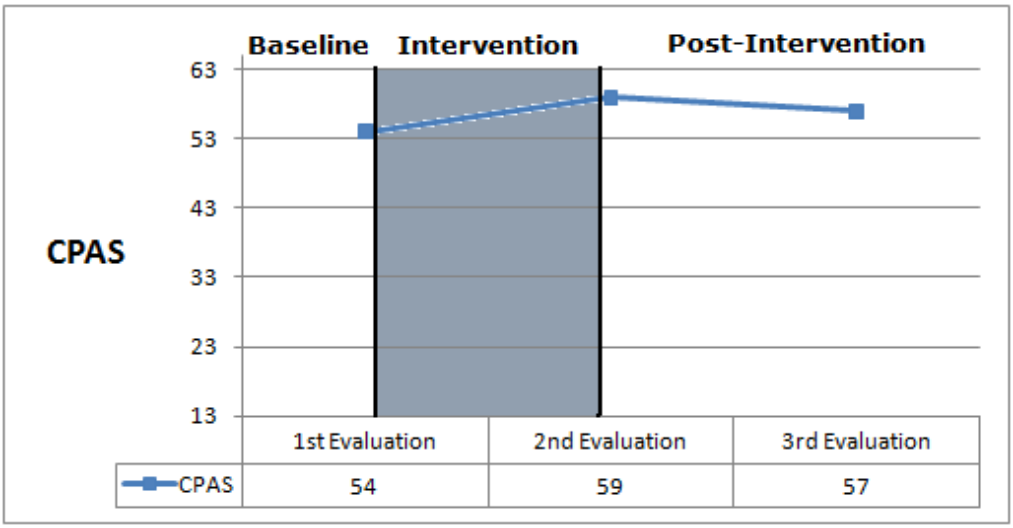


Figure 8.2: CPAS first, second and third evaluations

Compared with results of the second assessment lower symptoms of anxiety and depression were found (Figure 8.3).

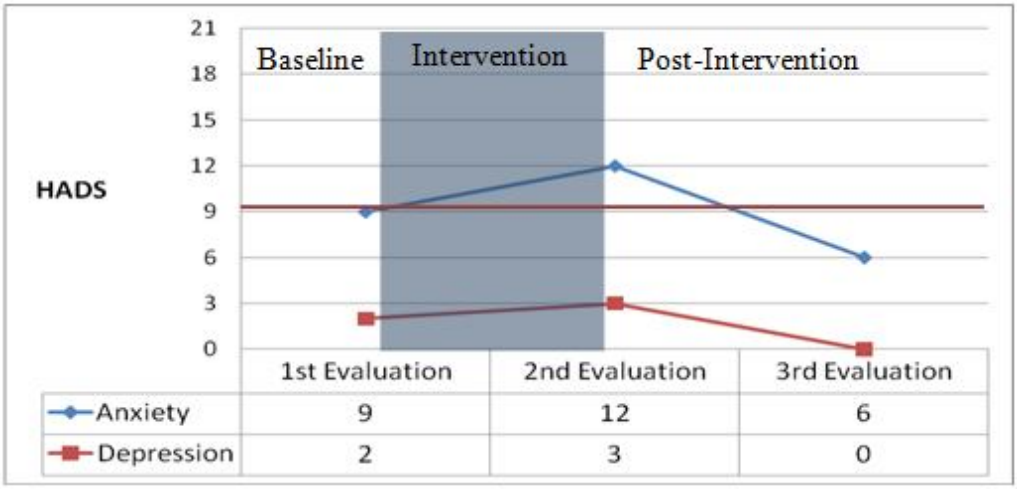
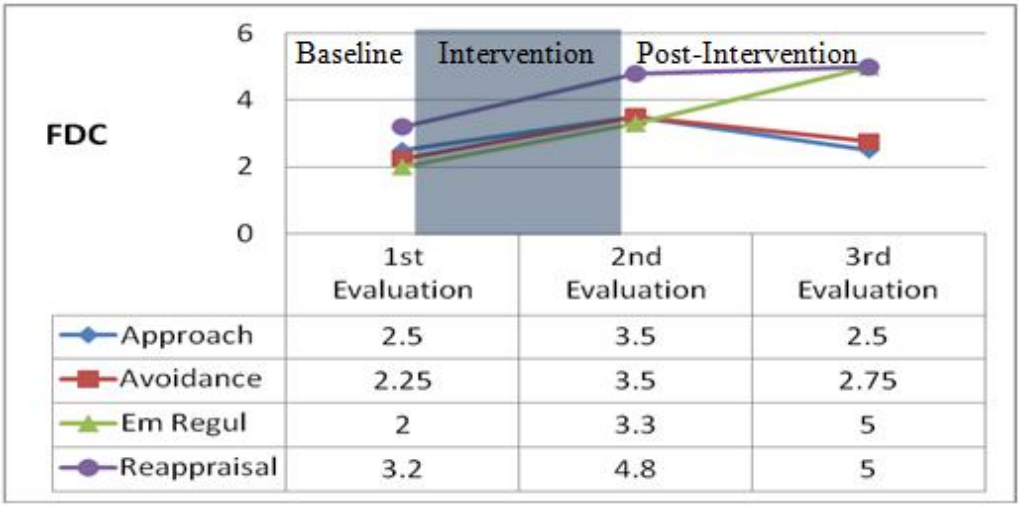


Figure 8.3: HADS first, second and third evaluations

In terms of coping strategies a better use of emotional regulation and reappraisal and lower usage of avoidance were found (Figure 8.4).



	1st Evaluation	2nd Evaluation	3rd Evaluation
Approach	2.5	3.5	2.5
Avoidance	2.25	3.5	2.75
Em Regul	2	3.3	5
Reappraisal	3.2	4.8	5

Figure 8.4: FDC first, second and third evaluations

In summary, DB showed a significant increase in CD4+ lymphocytes in the second evaluation, directly after finishing the Intervention Programme. PSS, approach, emotional regulation and reappraisal showed similarly improved results in the second evaluation. Scores for depression remain similarly low; however, higher levels of anxiety and avoidance were found. At the third evaluation point, the CD4+ continued to increase, as did PSS, emotional regulation and reappraisal. Overall, lower signs of anxiety and depression were found. This may demonstrate the long-term positive psychological effects of the Intervention Programme. Similar assumptions might be made for CD4+ counts; however, the latest data available showed a decrease in the counts (to 580). Nevertheless, this figure is still higher than that of the baseline assessment.

8.4.3. Post-intervention interview

After the post-intervention observation, CD4+ count and psychological improvement DB's progress was followed up by e-mail and phone to detect the progression in the defined parameters. The semi-structured interview

(Appendix U) was performed during September 2009 (two years after the first evaluation). Impressions about the intervention and their effects on DB's behaviour and health status were analysed. In order to identify significant themes a thematic analysis was performed. The interview was audio-recorded and transcribed. Five themes were identified: her opinions of the intervention, previous personality, improvements of personality characteristics, reasoning and interpretation, and effects of the intervention.

8.4.3.1. Opinions related the intervention

At the interview DB reported good recall, utilisation and perception of effectiveness of the learned techniques. DB perceived the intervention as a useful and effective strategy providing her with long term psychological benefits through the different techniques:

"*It was so interesting to know some techniques to relax and face problems. So valuable, I wish more people could benefit from it… …The biggest help for me: the relaxation techniques especially".*

The practicability of the learned skills was also stated by DB:

"I use them all…in everyday life… and also because I am in management in the place I work, I have to be patient, I have to be understanding, I have to be strong and when I am feeling probably tired, just keep going. And you probably taught me quite a lot of those things to be honest, I used them regularly".

8.4.3.2. Personality characteristics

The perception of the usefulness of the Intervention Programme may have been influenced by personality characteristics, making it easier for DB to understand, accept and use the new information:
"I am very strong, my self-esteem is very high and I don't let people affect me.…open minded, willing to try new things… but not many people are, are they? I am taking it on board and being open to changes."

After receiving the diagnosis of HIV, DB provided herself with a close and strongly supportive environment. She informed her partner (now her husband) and mother of the diagnosis, and received their support from the first moment. Using DB's words she "*intended to be surrounded by people who love her*". This reflects a specific personal meaning used as a structure to pursue goals for making life worth living despite its difficulties. These findings are coherent with new studies proposing personal meaning as an important variable for better understanding of the process of living with HIV/AIDS and intervention with people affected by the virus (Farber, 2010).

This shows the importance of personality characteristics in the effectiveness of psychological interventions; a factor that will be included in future applications of this Intervention Programme and an aspect that should be taken into account in the development of psychological interventions aiming to modify biological parameters. Hence, data from baseline evaluations may influence the choice of strategies in psychological interventions.

8.4.3.3. Development of skills

After the intervention DB described several improvements in her thinking and behaviour, including improved confidence, capacity of expression, mood and her own and others' perception of herself:

"I don't worry about my self-esteem and I used to really worry… I go to sleep at night and my mind is not going crazy. People at work say that I much more confident and also I speak my mind when I use to. My husband says that I am happier than I've ever been."

The improvements described by DB establish the positive effects of the Intervention Programme. This intervention found in DB the propitious personality characteristics for such a strong impact. Higher assertiveness, hardiness and the ability to express feelings have been linked with lower physical symptoms in women in stressful situations. These personality traits have been also linked with the presence of a trust or love relationship (Kenney, 2000; Fife, 2008). This is coherent with the 'living together' strategy, where the provision of a supportive environment improves psychological and physiological variables and, as biofeedback, positive psychological and physiologic states help in the self-provision of a healthier environment in an epigenetic relationship. In this sense, the interpretations each person gives to their own role in the construction of their environment and general health becomes the key variable.

8.4.3.4. Perceptions and interpretations

The described personality traits and their improvements are positively interpreted by DB as improving her health status.

"… I think my health is important to me and my family. But, also, looking after myself makes me feel better, better person as well; it makes me feel more confident and happier. I think the way you care about yourself and the way others see you have an effect on your mental health".

Interpretations like these have been linked to personality growth (Kraaij et al. 2008) and long-term survival (O'Cleirigh et al. 2003).

"… I am a strong person and my health goes hand in hand with the way my mind works: a stronger mind, a stronger health… I have not been ill… …not even a cold or anything, for probably two or three years now. I think the way I look after myself helps".

DB's responses express the beneficial cycle of positive thinking, protective behaviours and better general health status. DB's reactions to the intervention are a clear example of how this positive cycle can be empowered using psychological interventions with psychological and physiological benefits.

8.4.3.5. Effects of the intervention

DB gives an extraordinary importance to the trained techniques and the usefulness these skills have; this belief may have by itself a significant impact on DB's health status. She provides herself with a positive environment which improves her psychological and health conditions: DB takes care of herself because that makes her feel more confident; this helps her to see herself as a stronger person and she believes consequently that taking care of herself has effects on her health status. People in her social network have given her feedback as a happier person,

confirming that she has become a more confident person, which reinforces the care she takes of herself and promotes its positive effects.

"Because of who I am I've gotten better recognition in the company; other people at my job recognise that I am hard-working, [they recognise] *my aptitudes… so I think that is all part of it really.* [The techniques] *are useful in handling situations that are uncomfortable. I have perhaps been able to walk away and not let other people affect me as well; that is something that is still growing. Sometimes* [I] *do get affected by other people but… yes* [it is better now than it was]".

An interesting object of analysis is the change in DB's CD4+ counts and its coincidence with her utilisation of the learned skills. Before the Intervention Programme, DB's CD4+ counts were at 510 cells (July 2007); the flow cytometry immediately after the intervention indicated a rise to 710 cells (December 2007), then a new peak of 810 the following December (2008) and finally a decrease at the next exam to 580 cells (July 2009). DB linked these variations to higher or lower periods of self-care behaviours:

"I think is because I have not been practicing the skills [learned techniques]*… I was doing relaxation time, but I don't have time to do that very much now. I have not had my reiki sessions for a long time. That is probably why my CD4+ count is at 580… I probably need to step back again and slow down a bit really".*

The temporal coincidence between the rise and fall of CD4+ lymphocytes and the periods when DB was practicing the learned skills as well as other healthier behaviours such as reiki, and when she provided herself with more social support are striking:

"I was pretty involved in the women's group [of the PSO]*, but over the last nine months* [approx. January to September 2009] *I haven't really been doing that; I have just been work, work, work. I've not had any "DB time", I haven't done any reiki any counselling, any of my groups or anything".*

Equally striking are the connections she established between these variables:

"I do think there probably is [a connection]*, and if there is it would be interesting if I start to trying to do more looking after myself and see if I can go back again; I have to do that. Because, psychologically, having time for yourself, having time to relax, your body is going to work better and is going to be healthier, I imagine".*

These perceptions describe a strong and direct correlation between immunological and psychological functioning.

8.5. Discussion

This case report points at the improvements of psychosocial skills based on a psychosocial intervention programme and the potential for a strong increase of CD4+ lymphocytes counts due to the psychological intervention. The progressive rise in DB's CD4+ coincided with the end of a psychosocial intervention aiming to enhance immune functioning by training her in psychosocial skills to improve social support and coping strategies and to deal with anxiety and depression. This study is not proposing a cause-effect relationship, but a multifactor relationship where psychological social and immunological variables have continuous and strong interactions. The Intervention Programme needs further study and implementations to establish its effectiveness in modifying psychological and immunological

parameters; in the case reported, DB had post-intervention improvements in almost every psychological and immunological variable. Additionally, the improvements were maintained over a substantive period of time and are described by DB as strongly related with her attendance to and the skills learned during the Intervention Programme.

Based on the strategies used by DB for dealing with HIV/AIDS since her diagnosis, she appears to be a strong person and confident in the usefulness of psychological interventions; thus, the information and techniques provided were suitable for her character and may have reinforced her resilient behaviour. The fact that DB sees herself as more optimistic, confident and a calmer person is reflected in self-care behaviours like balanced eating habits and time for relaxation, and especially self-observation.

From the beginning of the Intervention Programme DB stood out among the other participants due to her tendency to accept and use the techniques implemented in the pilot Intervention Programme. She adopted these techniques not only as useful learning, but as new “healthy behaviours”. DB showed especial interest and confidence about psychoimmunological connections, their influence on bodily functions, and in the effects these techniques may have over physiological parameters.

This belief in the effects of psychological variables on the immune system by itself has effects on physiological functioning. In this regard a parallel can be established between faith and belief. Spiritual faith effects, related with personal belief and faith, have been differentiated from “religion or religiosity”—which is more related to institutional membership—and linked with lower depression (Yi, 2006), slower disease progression (Ironson,

2006) and better perception of quality of life (Szaflarsky, 2006) in PLWHA. In all these studies the accent was placed on the personal belief, the faith the person located with the spiritual divine rather than with doctrinal or religion membership. However, for this analysis the key is not faith in divine terms, but as a belief. It refers to the true confidence in something being the way it is believed to be. In this sense, the effects of belief can be used beyond religious areas; belief can be the central factor to have significant effects over people's health. This belief can be a strong instrument making more effective and powerful psychological interventions on biological health status.

In this way DB's belief in the effectiveness of the learned techniques may act in the same way as spiritual faith in the cited studies. Additionally, and as in other well known psychological theories such as Cognitive Behavioural Therapy (CBT), the level of success of these interventions strongly depends on certain of the participant's personality characteristics (Bulik, 1999; Bagby, 2008), personality disorders (Martinsen, 1998), cultural differences (Duarté-Vélez, 2010), level of symptoms (Ong, 2008; Prytys, 2009), sex, age and cognitive development (Koegl, 2008).

Several studies have been carried out to influence physiological functions, such as immunological (Antoni, 2002, Barak, 2006), cardiac (Bennett, 2001) and endocrine (Turner-Cobb, 2000) functions. These studies are successful examples supporting the psychoneuroimmunology (PNI) theory (Jadresic, 1993; Ader, 1995; Haas, 1997; Berczi, 1998; Fors, 1999; Yang, 2000; Reul, 2005; Lutgendorf, 2005; Kiecolt-Glaser, 2002; Reiche, 2004; Reul, 2005). Therefore, there is enough support for the theoretical and empirical base of the PNI approach. However, despite growing evidence, the specific processes governing psycho-immune interaction need further

research to achieve the required level of understanding for use as a reliable clinical tool.

In DB's case a rapid CD4+ increase occurred, jumping from 510cell/m³ in the pre-intervention moment to 710 at the post-intervention assessment and 810 at the third evaluation. A person living with HIV/AIDS stabilises around 500 CD4+/m³ and a seronegative person has counts between 800 and 1200cell/m³. For PLWHA it is not rare to see a rise in the normal levels of CD4+ when the person is following HAART; however, this case points to the relevance of psychological intervention directly addressed to immune modification. Techniques such as imagery, breathing and relaxation, conflict resolution, and self-esteem, may have different outcomes when they are directly exposed as techniques capable of influencing bodily functions. However, this is not a "*placebo effect*"; it is proposed to be a direct influence on health based on psychological intervention due to the psycho-socio-biological nature of health processes. Therefore, any psycho-logical or social modifications are unavoidably part of immunological (or biological in general) modifications as these are interconnected parts of the same process: the psychosociobiological process. No doubt there is a long way to go to develop a standard psychological intervention (or its parameters) to effectively modify immune (or other health) functions. However, based on this pilot application and case report, personality characteristics and perceptions about the effectiveness of the trained techniques are proposed as crucial factors for the success of the Intervention.

These data can also guide future studies on the relationship between psychological, social and immunological factors when living with HIV/AIDS, including perceptions and qualitative data, such as PSS and belief about

the effectiveness of these interventions. This also makes it possible, to some extent, to control these variables. A pre-session period within which to inform participants of the effectiveness of the methods and of the way that PNI works might improve the results of the intervention itself.

8.6. Conclusions

The question of whether an intervention based on reduction of levels of anxiety and depression and improving PSS can influence immune system functioning has been partially answered. Following this case report, there are enough data to argue for this relationship and many questions have been opened which will need to be answered by further research.

These results suggest the Intervention Programme as a useful strategy for improving psychological and immunological parameters and as a source of data indicating specific variables to consider in the development of psychological interventions addressed to immune improvements, such as the effects of PSO and peoples' beliefs, a field that needs deeper understanding. Another outcome is the correlation between certain of participants' pre-existent personality characteristics and their receptiveness for these psychological interventions, either in terms of adherence or effectiveness of the intervention itself or as a variable determining the specific techniques to use or the way these methods might be presented to the participants.

Social networks are proposed as having a relevant role in living with HIV/AIDS, with comparatively stronger effects on health of PLWHA when compared with other diseases; PSS is proposed as the key variable for

PLWHA. Therefore, interventions based on PSS may have different results depending on participants' specific health condition.

These results provide recommendations for the improvement of the Intervention Programme. Thus, future applications will consider the results of the baseline evaluation to define the approach to participants emphasising the recurrence of avoidance strategies in individuals related to their levels of PSS, depression and anxiety; to structure the order in which the sessions of the Intervention Programme (PSS, anxiety or depression) will be presented; to include in the baseline an evaluation of expectations and beliefs about the effects of psychological intervention over physiological functioning; and to study its effectiveness as a predictor of immunological results of the Intervention Programme. This modifications will be added to the ones described in Chapter Seven and are fully analysed in Chapter Nine.

Chapter Nine: Discussion and conclusions

From the studies executed during this PhD sufficient evidence emerged to achieve the main goal of this project: to increase the level of understanding regarding the process of living with HIV/AIDS and about the relationship between perceived social support (PSS), socio-culture variables and physiological functioning.

Some of these findings are:

1) Peer support organisations (PSO) of PLWHA appear to play an important and underexplored role in PLWHAs' health status. These organisations are the result of a cooperative strategy used by PLWHA to self-provide social support in an example of a "living together" strategy;

2) A measure of PSS was developed and theoretical analysis leads to a linkage with Maslow's hierarchy of needs, an association that requires further research to establish clearer parameters; and

3) Personality characteristics and personal beliefs were found to be critical factors in the success of PNI based interventions, situating participants' expectations as one of the strongest elements.

Further research is needed to fully understand the interaction of psycho-socio-immune variables in this multidimensional process of living with HIV/AIDS; however, this research contributes novel viewpoints and significant findings related to the influence of socio-cultural characteristics on the process of living with the virus, its treatment and the way PLWHA are perceived and perceive themselves.

9.1. Analysis of research questions

Similar to Sepa (2002) who linked the development of type 1 diabetes with lack of social support and Oksbjerg (2008) who studied cancer incidence in 3.2 million Danish citizens over 12 years, discovering a higher incidence among those living alone compared with individuals living with a partner, the studies performed within this PhD suggest a positive relationship between PSS and the functioning of the immune system. In the same way, it is possible to affirm there is a strong interaction between socio-cultural variables, PSS and health status in PLWHA. Country-specific socio-cultural characteristics determine the way in which HIV/AIDS is perceived and supported by the society and, therefore, the way PLWHA interact in such society. These interactions are graphed in Figure 9.1.

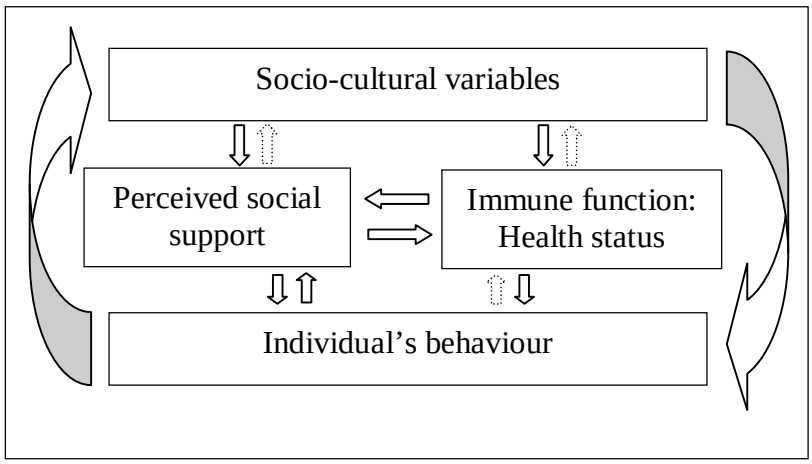


Figure 9.1: Socio-cultural and health interactions diagram

These interconnections have social, psychological and health-related effects on individuals in general. For these reasons, PSOs of PLWHA are suggested as playing a key role in the health status of their members; it is also suggested that PSS is linked to individuals' level of self-actualisation. Thus, the research questions were addressed as follows:

1. How are perceived social support (PSS), anxiety, depression, coping strategies (approach, avoidance, emotional regulation and reappraisal), CD4+ lymphocytes, viral load level and HAART expressed and correlated in PLWHA from England and Chile?

Compared with data from general population in the UK (Singleton, 2000), Chile (MINSAL, 2006) and the student group evaluated in the CPAS questionnaire validation (Chapter Three), PLWHA showed poorer PSS, approach, emotional regulation and appraisal and higher levels of anxiety and depression. In the present study, and similar to Balbin (1999), Cruess (2003), Evans (2002) and Mak (2007), HIV/AIDS have been found to have a high impact on psychological health of PLWHA. Moreover, and as in Cole (1996-b), Goodkin (1998), Ullrich (2002), McCain (2003), Motivala, 2003, Robbins (2003), Lugendorf (2005), Robins (2006) and Prachakul (2007), these variables were linked to immunological detriment. Lower psychological symptoms were found among Chilean PLWHA (non members of PSO) as compared with British participants (members of PSO). Despite the differences between these groups (from two countries and users and non-users of PSO), the results are coherent with Crook (2005), who defined a higher level of vulnerability (described as higher loneliness and poorer reported health) as a common characteristic of PLWHA seeking help from community-based AIDS services.

These data are coherent with the high levels of stigma and discrimination against PLWHA, which are described by members of healthcare teams and representatives of PSO in England, Romania and Chile as a common factor affecting PLWHA. Discrimination against PLWHA was strongly associated with lack of understanding about HIV/AIDS. Nevertheless, many of the health professionals pointed out discriminative behaviours from health

professionals themselves; psychological affliction among PLWHA thus appears as a logical consequence of the stigma around HIV/AIDS. Lower perceived support has been linked with depressive symptoms and stigma in HIV/AIDS. Perceived HIV-related stigma and internalised stigma mediate the effects of social support sources (Vyavaharkar, 2010); because of this, individuals perceived as stigmatised take less advantage of their available social support. In addition, living with HIV/AIDS has been correlated with lower quality of life (Kowal, 2008) completing a vicious cycle in the lives of PLWHA.

These findings give support to the establishment of HIV/AIDS as far more than only a biological condition. The process of living with HIV/AIDS involves several highly connected psychological and social factors in an epigenetic relationship. Additionally, PSS was positively correlated with emotional regulation and reappraisal, whereas negative correlations were commonly found with anxiety and depression among PLWHA. These results are coherent with the data reported by Gardenier (2010), stating higher levels of adherence to HAART and healthcare among individuals having higher levels of social support. This establishes a circle where reduced social support leads to lower adherence to treatments, thereby reducing their efficacy; increasing chances of opportunistic diseases and psychological symptoms such as anxiety and depression; and reducing social contact. Results for avoidance and approach showed inconsistency, possibly due to the utilisation of direct and indirect approaches to deal with conflictive situations. Similar to Robbins (2003) and Eisenberger (2003), the study of PLWHA in England and the Case Report showed a positive correlation between PSS and the functioning of the immune system; CD4+ lymphocytes expressed different results in the different samples. However, a clear tendency was observed indicating higher number of CD4+ when

better PSS and lower depressive and anxious symptoms. Lower anxiety and depression were found among PLWHA who were living with someone else compared with those living alone; who had a higher perception of belonging to their groups; and who reported a relationship with the group based on mutual esteem. These correlations are interpreted as a biofeedback relationship between psychological, social and biological areas, producing a chain effect that can bring positive or negative effects for PLWHA, as described by Pakenham (1998). Based on the result of this research a novel and holistic approach in healthcare for PLWHA, which should include PNI knowledge as capable to modify health status, is proposed. Due to its psycho-socio-immune implications, HIV/AIDS is proposed as an especially favourable scenario for the utilisation of bio-psycho-social approach to improve patients' general health.

2. How do socio-cultural characteristics interact with and influence the approach, the cooperative strategies, the targets, and the provided and PSS from health professionals and PSO?

The approach of health professionals: Despite the growing inclusion of psycho-social aspects and the fundamental psychosocial work performed by social workers and/or psychologists in Chile, England and Romania, the focus of healthcare for PLWHA and their treatment is on the biomedical approach; clinical care is supplied for free and in similar conditions in all three countries. The traditional clinical approach to PLWHA in these health teams has gradually come to include a more holistic approach to healthcare; however, the bio-psycho-social perspective still remains underused as a clinical strategy. It is used as a parallel support, but not as a primary strategy able to influence people's health. Some distinctive factors refer to the socio-cultural approaches used by each country; in

Chile, for example, PLWHA are highly involved in the fight against HIV/AIDS, including taking part in health committees which in turn tend toward a more participatory approach. In Romania, the strategy focuses on clinical assistance with specialised healthcare teams for PLWHA in departments for PLWHA. In England the strategy has begun to move in the other direction, offering full healthcare undifferentiated from any other chronic state, in a strategy which aims to normalise the approach to HIV/AIDS, possibly as a way to reduce stigmatisation. This strategy may have strong effects on individuals' perception about what HIV/AIDS is for both PLWHA and the seronegative population; if it is treated as 'just one more disease', it may be perceived as 'just one more'. However, based on the results of this PhD research project, the level of understanding and stigma about HIV/AIDS in the general population (and also among health professionals) may be the first and most difficult barrier to overtake before successful results emerge from this strategy.

According to the interviewed healthcare professionals and PSO representatives, the levels of prejudices and stigma around HIV/AIDS still have strong effects on the epidemic of these countries; an example of this was the description of 'at risk' and 'out of risk' groups and the approach these groups have to HIV/AIDS in the three countries. Higher levels of knowledge and understanding about AIDS were described among "at risk" groups (homo-bisexual men, young people); however, those described as "out of risk" (heterosexuals, especially women) in recent years have been the population with the highest number of new cases (UNAIDS, 2008, p33). Social factors, such as educational levels, political circumstances and use of drugs, were identified by health professionals as affecting the effectiveness and adherence to HAART and healthcare, pointing at the effects of social factors in the evolution of the HIV/AIDS epidemic.

Similarly, Gardenier (2010) described social support as having direct correlations with adherence to HAART.

Examples of the services offered by PSO of PLWHA include the provision of social networks, repairing or preventing social isolation; the provision of social and emotional support, reducing stigma and discrimination and facilitating the process of self-acceptance to live with HIV/AIDS; and legal support in case of rights violation. These services are proposed as key factors for the preliminarily results showing significant effects on PLWHAs' general health status (Chapter Seven and Eight). The PNI perspective has given enough evidence to establish the relationship between psycho-socio-immune variables. This understanding supports psycho-immunological strategies of healthcare in order to reduce the negative health impact of psycho-social variables where the biomedical model is proposed by having limited or no clinical impact. The benefits of a PNI approach to reducing individuals' symptoms can also have effects such as reducing the workload levels of clinics and hospitals due to fewer consultancy rates; however, the PNI approach has thus far been underused to cope with these variables. Despite some cooperative work which has tended to develop psycho-social benefits, all three countries focus their approach in healthcare for PLWHA in the biomedical perspective.

The approach of PSO: Networks of support are well established in Romania, Chile and England. However, peer support as a primary approach for organisations of PLWHA is more common in Romania and Chile. This peer support strategy results in PSOs (understood as PLWHA offering support for PLWHA across an organisation specifically addressed to that purpose) being proposed as the key factor for a higher bio-psycho-social impact on members of these organisations. Unfortunately, PSOs have been

underused and understudied as a clinical strategy. The peer support strategy is also used by some emblematic British organisations; however, most of the networks of support available for PLWHA are offered by the NHS and still fall under the umbrella of physician-patient relationships, far from the peer support strategies offered by PSO.

In a cross-cultural comparison, De Castro-Silva (2008) observed that the level of political participation of PLWHA is related to the level at which their rights are respected by society; the lower the rights' respect, the lower the participation. Coherently, the number of people who are active members of PSO sis lower in a more discriminative society; however, the level of involvement of these few members in the PSO itself seems to be higher in societies with higher issues against PLWHA. In these cases, individuals are also providers of services and not only passive receivers of support. Along the same lines, in the present study it was observed that differences in terms of approach, related to socio-historic events, have strongly influenced the way in which social support is provided by PSO in the studied countries. This reflects two main analyses: first, PSO represent a tailored solution created by PLWHA to respond to the specific need of each particular environment; and second, this is an example of consequences in terms of learned hopelessness, of discriminative environments; under these conditions most individuals opt to remain silent; nevertheless, there are some who begin to make a change, and those have specific characteristics which differentiate them. In Chile the current participation of PLWHA in AIDS-related issues in the country is due to the work performed by ASOSIDA in educating the population and demanding participation and inclusion in a closed society. In Romania the role played by UNOPA as the representative and voice of PLWHA is based on parents' response to medical negligence against their children in the 1980's and

1990's. In England, the empowering process set in progress by THT is due to a reduced initial participation of PLWHA as representatives and supporters of themselves, a role strongly played instead by NHS-based support. At the base of all these strategies there is cooperative work, which, from the defined view of this PhD study, represents an utilisation of the 'living together' strategy described in Chapter One; this strategy involves cooperative work to obtain collective benefits and to provide social support and safety to the group. This strategy, however, needs a starting point, a person or a group with specific coping skills which can put this change in motion. The strategies used in the different countries may become a useful source of information for PSOs and for each health system in the three countries.

3. How do cooperative strategies to provide social support interact with the health status of PLWHA in England, Chile and Romania?

PSO in Romania, Chile and England have different structures, approaches and strategies, but a similar target: the defence of PLWHA from social stigma. To this end, legal advocacy, empowerment and education are the most common strategies used by the organisations. However, the role played by PSO has been far greater than this. PSO have been crucial in terms of reducing stigma, in the dissemination of updated information about HIV/AIDS, and in increasing understanding and preventive behaviours in the general population, apart from being a direct social support for PLWHA.

HIV/AIDS severely limits the sources from which someone living with the virus receives emotional support, as well as opportunities to receive that support (McDowell, 2007). This rupture in social networks turns social

support into one of the most important psychological variables in the process of living with HIV/AIDS; Additionally, the relationship between psychological and immunological variables; the effects of PSO in restructuring people's networks; and the reduced number of social networks for PLWHA convert PSO into natural and effective sources of integrative healthcare, a conclusion that is sustained by the results of this PhD where PLWHA who have been members of PSO for a longer time have better psychological and immunological results compared with PLWHA who have been members for a shorter time. These results are consistent with the argument sustained by Leserman (1999) about the direct correlation observed between faster progression to AIDS and less cumulative social support; in a study of 5.5 years the chances of progressing to AIDS among individuals below the median in support were double to triple compared with individuals above the median. However, further research is needed to establish the impact of PSO over general health of PLWHA, since this is a under explored area. Further research should evaluate the described effects of PSO as provider of social support and its effects on health of their members.

The evidence from the study of PSO and healthcare team members in England, Chile and Romania showed a strong interaction between socio-cultural variables, PSS and health status of PLWHA. Socio-cultural variables not only influence roles and goals of PSO, but also country-specific healthcare approaches, politics and strategies to fight against HIV/AIDS, giving a wide range of influence to psycho-social variables in the process of living with HIV/AIDS.

4. Are there immunological and/or psychological differences relating to the length of membership of PSO of PLWHA?

Direct effects of PSO on PLWHAs' health status were seen. As mentioned, length of membership of PSO was positively correlated with psychological and immunological health status of PLWHA in England; participants of the pilot application in the East Midlands PSO who had spent more time in the organisation had, in general, higher CD4+ lymphocytes counts, better PSS, lower anxiety and depression and more use of emotional regulation and reappraisal in comparison with participants who had passed less time as members. These correlations were not related to age or time of diagnosis, nor to years under HAART. Ueno (2001) reports the influence of the perception of social support availability. Going beyond social support itself and PSS, Ueno studied the PSS availability, which is how support the person perceives may be available in his/her environment. Ueno maintains that when individuals cope together with the same conflictive situation; share their experiences of been supported and/or the places were support is offered; and/or simply observe others being supported they create a "*collective knowledge of support availability*" resulting in an active creation and modification of individuals' perceptions about availability of support. This reconstruction of social reality, in combination with the effects of tangible social support provided by PSO, may be the key factor explaining better psychological and immunological results among long-term members of PSO, having strong influence on individuals' behaviours and health status. Based on these results, PSO for PLWHA are proposed as having influence on general health status of its members. No studies have been found in the literature related to direct effects of the use of peer support strategies by PSOs of PLWHA on their members' health statuses; however, the strategy of peer support via PSOs has successfully reduced discrimination among women living with HIV/AIDS in Thailand (Liamputtong, 2009). This strategy has also been used by centres

providing support to PLWHA (as NHS does in the UK) and has proved its effectiveness on reducing stress among adolescent AIDS orphans in Uganda (Kumakech, 2009). Additionally, a peer support intervention has been piloted among adolescent hospital patients in France with promising effects on HIV viral load counts reduction (Funck-Brentanoa, 2005). This hospital-based use of peer support strategies has also proved its benefits in improving information provision and referral systems within the health services, suggesting that the establishment of these self-help groups can reduce perceived stigma and facilitate the use of offered services and healthcare in HIV/AIDS (Nguyen, 2009).

An analysis of the history of these organisations shows that they have been able to deal with socio-cultural sensibilities affecting the well-being of PLWHA and have been successful in provide them with better quality of life. These organisations have been able to increase understanding about HIV/AIDS in society, providing a less discriminative environment. These organisations have been a powerful, but underused, strategy for improving the general health of PLWHA a statement which is confirmed by the direct correlation between the number of CD4+ lymphocytes and the length of membership on a PSO in England. Despite the limitations on addressing this question, the results suggest a link between the time spent in a PSO and the health status of PLWHA. Further research is needed to fully understand the links between these variables.

5. Which adjustments are needed in order to successfully and effectively administer the Psychosocial Intervention Programme to a British population? – Pilot application.

The pilot experience with the Intervention Programme gave substantive information regarding the structure of the intervention. Several

characteristics of the participants need to be taken into account in the design and structure of the Intervention Programme to solve some unwished outcomes appeared during the pilot application.

- Length of membership in the PSO: The volunteers willing to take part in the programme—50% of the total available—were newer members of the organisation. Future applications of the Intervention Programme may need a recruiting process focused on older members to increase the number of this group within the participants or take into account the influence of this variable in the analysis of the results.

- Psychological status: people with better psychological health attended more sessions compared with those with higher levels of anxiety, depression and lower PSS. In other words, participants with higher psychological symptoms had lower levels of adherence. Depression, stress and lack of social support are commonly studied as HIV/AIDS related afflictions (Reyland, 2002 and Pukay-Martin, 2003) and this pilot points towards the existence of a repetitious cycle between higher depressive and anxiety symptoms and low adherence to the Intervention Programme. This may indicate the need for a baseline evaluation as a predictor for adherence, withdrawal and effectiveness of the intervention and therefore to the need for those data before beginning the Intervention Programme. An evaluation of personality characteristics and beliefs about PNI-related issues will be also included at the baseline evaluation, since—based on the data—these variables may influence final results of the intervention.

- Time under HAART: PLWHA under HAART for a longer period showed better psychological results. This may indicate an indirectly confounding variable; even though HAART did not directly correlate with immune function, correlations were found between psychological and immunological

variables. If psychological variables are influenced by time under HAART, this influence should be included in the analysis and studied as a side effect of HAART.

These data will be useful in future implementations of the intervention programme in terms of organising participants and anticipating possible drop-out rates among more psychologically affected participants. Since the length of the intervention was mentioned by participants as an obstacle in continued attendance of the sessions, a shorter intervention is proposed as a way of increasing adherence to the programme; the original design has an extension of 13 sessions (Appendix M) with an average of four sessions per area (anxiety, depression and PSS) and pre- and post-intervention assessment of psychological and immunological variables; the short version has six sessions (Appendix S) with two sessions per area and pre- and post-intervention assessments. The original version provides the participants with information about how anxiety, depression and social support work; it gives signs, symptoms and a summary of theory about these variables; it undertakes several discussion activities to analyse personal experiences in depth; it presents several techniques for coping with anxiety and depression, others for improving social support, all of which are also practiced with the participants. In contrast, the short version presents a summary about how anxiety, depression and social support works and key techniques are presented and practiced. Some in-depth analysis is undertaken, but for the most part the work of the intervention is framed as personal work and is encouraged to be carried out individually. This new intervention needs new pilot applications to evaluate its effectiveness in modifying both psychological and immunological variables. The full intervention seems to have positive effects on psychological and immunological variables and therefore the

content of the intervention (techniques and variables included) does not need modification. This intervention is advised to be carried out in full to improve results, and emphasis should be given to the in-depth analysis of individual experiences as well as to connecting these experiences with the theory using examples from everyday life.

The preliminary results of the pilot application were partially linked to immunological and psychological improvements among participants. Chapter Eight – Case Report describes the strong increase of the CD4+ lymphocyte count in a participant after the pilot application of the Intervention Programme and the results suggest that specific previous personality characteristics and personal beliefs facilitated the adoption of the techniques practiced during the intervention. Personality characteristics and psychological states, such as strategies for dealing with difficulties; beliefs about psychological influence over biological parameters; internal or external control locus of control, levels of learned hopelessness; and levels of stress and anxiety and PSS are crucial information for intervention programmes under a PNI approach and need to be emphasised in the final version of the Intervention Programme. In the same way, psychological techniques are proposed to have a different outcome when, based on scientific studies, they are presented as capable of modifying immune parameters. All these factors may substantially determine the success of the intervention in potentially improve immune parameters. Similar to Donaldson (2000), these preliminary results may also indicate that techniques such as imagery, breathing and relaxation, conflict solutions and self-esteem improvements can have effects on health status and can be a direct proof of the bridge between psychological and immunological variables argued in psychoneuroimmunology.

These results show the influence of participants' preliminary health and personality characteristics on the outcome of this Intervention Programme based on PNI approach. They also show how this interaction modifies the structure of the intervention. Therefore, future applications will include a gap between the baseline evaluation and the first session; psychological and immune data will be used to define the way and the order the information and techniques are presented to participants.

Based on growing evidence maintaining the relationship between psychological and immunological variables (Balbin, 1999; Baum, 1999; Donaldson, 2000; Kopnisky, 2004; McCain, 2005 and Robins, 2006), this Intervention Programme is proposed as capable of influencing the multidimensional relationship of the psychobiological process when living with HIV/AIDS. The hypothesis is that a Psychosocial Intervention can improve biological parameters by modifying psycho-social factors and, even though the results of this pilot application need further research to clarify the effectiveness of the intervention, these preliminary results are useful as base from which to develop a Psychological Intervention Programme able to effectively modify psychological and immunological variables.

The Pilot Application has provided enough data to modify the originally proposed Intervention Programme and improve both effectiveness of the intervention and participants' adherence. The pilot has also given partial results supporting the possibility to modify both psychological and immunological parameters as a result of taking part on the Intervention Programme. Further research is needed to study the effectiveness of the 6-session version of the Intervention Programme and/or to fully apply the 13-session Intervention Programme using the understanding of the process

of living with HIV/AIDS and of group interventions acquired during this research. The pilot intervention was a useful way to work directly and extensively with PLWHA and their organisations in England, acquiring invaluable understanding of HIV/AIDS in this country.

9.2. Applications and implications

Applications and implications of the results of this PhD are presented relative to seven main areas linked to direct outcomes of this research, utilisation of these outcomes, and direct ongoing research related to the described results.

1. The Questionnaire of perceived social support (CPAS): The development and validation in British population of the CPAS. This questionnaire, originally developed by the author in Chile (Cortes, 2003), was used in this research to evaluate PSS among PLWHA and students in England. The approach defined for this research was based on individuals' perceptions of and behaviours in their environment. This approach gives a tailored view not focused on quantitative indicators of social support, such as number of networks or people available offering support, but on individuals' perception of and reactions to the support received.

The CPAS offers a valid evaluation of PSS. Although especially developed for PLWHA, its design allows for use in other populations. This self-administered 16-item scale offers the chance to evaluate PSS as positive or negative and to contrast the final score with the number of networks the respondent is taking part in and how regularly he or she communicates with them. A disadvantage of the use of this questionnaire is its current lack of population norms.

An interesting outcome of the impact of PSS on general health status of PLWHA is the result of the factor analysis of the CPAS answers. As was described in Chapter Three, a relationship between the items on the three resulting factors and the three top levels of Maslow's classification is proposed for further exploration: *belonging* (as basic affective needs, *safety* and acceptance as individual), *esteem* (as acceptance, companionship, tangible help and affection) and *self-actualisation* (as group membership and possibilities for growth; development and solutions). These results need replication and further research to determine the capability of the CPAS as a measure of Maslow's actualisation.

As sustained in the Chapter One - Literature Review, Axelrod's (1981) theory of cooperation and Nash's (1950) theory of equilibrium point towards working cooperatively as the most successful and unavoidable strategy among individuals. These models have been used in evolutionary theory to support social evolution. Maslow's Hierarchy of needs includes "*safety needs*" as its second level. As was described in Chapter Three, these needs are among the strongest controlling any organism and can even relegate physiological needs, the first level described by Maslow (1943), to second place. Safety needs are strongly connected with group interactions; it is in group cooperation that cognitive capacities and feeling of shelter rise (Richerson, 1997). Interdependence between feeling safe and in-group cooperation is proposed in this research as the base for human social and cooperative behaviour and the theoretical base for what Maslow called a "safety-seeking mechanism capable to use all its skills for the seeking of safety". In this way a hostile environment will lead to cooperative work among those being aggressed, as in the case of PLWHA and the formation of PSO. Consequently, the quality of the support perceived by PLWHA may reflect the level to which their safety needs are

covered; when these basic needs of safety are reasonably covered, love, esteem and finally actualisation can also be fulfilled.

From this point of view it is not surprising to see a high level of coincidence among the items forming the factors arisen from the statistic analysis of the CPAS and Maslow's Hierarchy of needs. This may also lead to a relationship between socio-cultural factors (the way in which social support is provided and perceived; the approach of the healthcare team; and PSO) and the level to which people feel fulfilled their needs according Maslow's scale. Additionally, and based on the correlation between PSS and immune function, this proposed link between Maslow's theory and social support opens a link between PNI, social support theory and Maslow's Hierarchy of needs. In this way the CPAS may indicate a measure of actualisation using individual's perception of the support received from social networks and significant people. These results suggest a link between PSS and the level to which people satisfy basic and higher-level needs for self-actualisation. Further research may undertake a more in-depth study of this suggested relationship.

2. The role of PSS in the process of living with HIV/AIDS: The evidence suggests HIV/AIDS as a state of higher psychological and social affliction when compared with population data and the student group evaluated in England. In this way living with HIV/AIDS is not only a clinical condition, but also a psycho-socio-immune process wherein psychological, social and immunological variables affect each other in an epigenetic relationship. PSS is proposed as the key variable, with higher relevance than the number of networks supporting the individual. This perception regulates other psychological symptoms such as depression, anxiety caused by stress and in this way determines the impact of these psychological variables when

living with HIV/AIDS. Psychological programmes, addressing psycho-immunological improvements of PLWHA, should include as one of their focuses the improvement of perceived and provided social support, since improving the support obtained from social networks will facilitate the improvement of psychological and immunological variables and, as suggested, may also influence the level of satisfaction of basic and higher-level needs.

Human processes are by definition multidimensional; psychological, social and biological factors are theoretical divisions, useful for classifying and understanding a complex process; however, these factors are part of the same organism. They have extremely connected interactions and conform to one multidimensional system. This proposed approach aims for the inclusion and utilisation in healthcare of the understanding of human multidimensionality offered by the psychoneuroimmunological perspective.

3. The use of PSO of PLWHA as useful strategy to offer support and improve health of its members: The preliminary condition of the results is taken as an incentive to collect more information towards the confirmation of these findings. This suggests the inclusion of cooperative work as an integrative strategy of support between PSO and formal healthcare clinical institutions. This suggestion is based on three statements: first, the possibility of significant psychological and immunological benefits of psychological interventions aimed at improving psycho-immune variables; second, the described benefits in general health of the strategy of peer support offered by PSO in all three countries; and third, the benefits of cooperative strategies to self-provide social support, described herein as the ‘living together’ cooperative strategy. These statements address possible benefits in quality of life and lifespan of PLWHA. Several

approaches can be adopted, for instance: links between clinical personnel in charge of giving the HIV diagnosis and peer support organisations' services for newly diagnosed individuals; links between a hospital's psychologists and an organisation's one-to-one peer support services; links between a hospital's social workers and an organisation's legal advocacy or helpline services. These strategies may be limited by the legal structure of healthcare centres and PSO of PLWHA, specific cultural sensibilities or standardised procedures that may obstruct the implementation of cooperative strategies.

4. The importance of cultural factors in the application of psychosocial interventions in HIV/AIDS: the results suggest an analysis of the "state of the art" in the way each country have been dealing with HIV/AIDS. Any psycho-social intervention may consider how open each society is to dealing with HIV/AIDS before defining the approach to be undertaken. Indicators of openness to HIV/AIDS in a specific country may include the number and level of participation in society of PSO; the visibility of sexual minorities; and the occurrence and content of governmental campaigns.

In England the strategy of normalisation in the treatment of PLWHA as 'just one more' chronic health status, as mentioned, can have significant positive effects on PLWHA. However, the need for greater education of the general population and also among health professionals is a task that needs to be performed before the 'normalisation' strategy can give the expected results (reduction of stigma around HIV/AIDS). England offers a key moment for research to evaluate whether this change in the way HIV/AIDS is perceived by healthcare teams can influence levels of stigma perceived by PLWHA.

In Romania the role of UNOPA has shown coherent behaviour with the condition of parents of children living with HIV/AIDS, assuming an advocacy role of PLWHA. This approach has proved absolutely necessary due to the lack of understanding from society and the government that UNOPA have to deal with. However, those infected between 1986 and 1991, now young adults, will possibly demand a change in this paternal approach. This may have important effects on UNOPA structure and politics, and bring a crucial opportunity to give PLWHA in Romania a more important role in the defence of their rights. In addition, the positive effects of a greater and more personal involvement and compromise of PLWHA can be seen in Chilean and British PSOs. If a more active role from PLWHA is started in Romania, this moment may lead to a significant amount of information in terms of the possible influence of a more active role of PLWHA in the defence of their rights versus a more passive one in the context of a discriminatory environment. For these reasons, this research highlights the need for UNOPA to anticipate this generational change and to take the best advantage of it.

In Chile, ASOSIDA offers psychological, legal, and social support, and focuses its efforts on public policies in order to improve quality of life of PLWHA. This has resulted in PLWHA taking a more active role in the fight against AIDS. The advance in cooperative work with Chilean authorities of ASOSIDA offers a unique opportunity to extend that collaboration to a new level and utilise—and study—the effects of peer support as a strategy for improving the health status of PLWHA members of these organisations. However, the qualities ASOSIDA has in this area have not been studied. One suggested consideration would be the practicability of cooperative work between ASOSIDA and formal healthcare institutions. This based on

the understanding and utilisation of the knowledge given by the bio-psycho-social approach in healthcare.

5. Relating PNI and social support theory with socio-cultural factors: as mentioned in point 4, socio-cultural factors influence the strategies each country undertakes to deal with HIV/AIDS. This is proposed to have influences not only at psychological or social levels, but immunological and general health ones too. Social support, and specifically PSS, was found to have a crucial role in individuals' health and need satisfaction, further research is needed to study these preliminary findings in depth. However, these findings point to a direct influence that public policies may have over PLWHA interaction and integration in society and therefore, over the health status of PLWHA.

6. The Psychological Intervention Programme as a clinical strategy to improve psychological and, possibly, immunological parameters: this group intervention was developed for PLWHA, however, it focuses on psychological afflictions common to the general population, offering strategies and techniques to improve social support; to deal with depression and anxiety; and to optimise the use of coping strategies. It can, therefore, be a useful programme for any group of people. As a minimum, one person qualified in social science is required for the application of this programme. The coordinator(s) of the programme need(s) as an absolute requirement, training in the management of depression and anxiety and an understanding of social support and coping dynamic in terms of the specific participants' health characteristic (e.g. HIV/AIDS, cancer, physical disabilities, etc.).

Limitations of the use of this intervention programme are primarily linked to its being a newly developed strategy and, therefore, the preliminary status of the results in relation to its effects. Further research might perform follow up applications and increase the amount of data about the intervention's effects on both, psychological and immunological variables.

7. The role of an ideographic approach in the study of psychoneuroimmunology: this research defined a systemic approach as necessary to achieve the target of enhance the understanding of the process of living with HIV/AIDS in the relationship between psychological, social and immunological variables. However, to achieve this holistic view the inclusion of individual characteristics was defined as crucial in order to properly study the relationship between psychological and immune factors. These individual factors should be taken into account to define group interventions and, despite sample concerns, individual characteristics give a more intimate and realistic view of the degree to which intervention may impact participants and may define the success of the intervention; samples are always formed by individual cases and this should be reflected in the specific emphasis given to the different skills and training offered to the participants.

9.3. Future research

Future investigative steps based on the data which emerges from this PhD will address the following main tasks:

First, the implementation of the Psychological Intervention Programme; based on the learning process of the pilot application, the next logical step is its full implementation. This will continue the research process towards

the development of a psychological intervention effective in modifying not only psychological parameters, but immunological ones as well. Further research will adjust, for example, the optimums number of sessions to ensure adherence and effectiveness. This intervention should be implemented with patients in England and at the Universidad de Chile Clinical Hospital in Chile.

Second, the study of the psycho-immunologic impact of PSO in PLWHA member of these groups. This is one of the most important outcomes of this study. PSO have been found to have a substantive role in PLWHA's general well-being, including contributing to psychological and immunological improvements. Additionally, the effects of these organisations on general health have not been studied; this offers a new approach for the study of PSO of PLWHA. This research is proposed to be undertaken working with members of the PSO ASOSIDA in Santiago, Chile.

Third, based on the effects of PSO on the health status of PLWHA, as described above, a cooperative strategy between formal healthcare institutions and PSO of PLWHA is proposed in order to take advantage of the positive effects of the peer support strategy. Prior to the execution of this cooperative strategy, the effectiveness and practicability of cooperative work between these two actors will be studied working with ASOSIDA and the Universidad de Chile Clinical Hospital in Santiago, Chile.

Fourth, the described relationship between PSS and Maslow's Hierarchy of needs will be studied by the administration of the CPAS in the samples mentioned in the previous three points. PLWHA will be the main focus of further study to discern whether a measure of actualisation is possible using the CPAS and Maslow's theory. This research can be linked with the

proposed “living together” strategy. As mentioned, living together as a cooperative strategy to self-provide social support has been found to be successful, according the results seen in members of PSO and the analysis of PSO in Chile, England and Romania. In this sense the extent to which PSO succeed in self-providing social support may have effects on the levels of satisfaction of basic needs for belonging, safety, acceptance, affection and self-actualisation. This approach may offer to social support and cooperative strategies a novel approach in terms of the impact that social support has in general well-being.

9.4. Methodological issues

1) The evaluation of PLWHA and the pilot application in England were partially limited by the fact that PSO of PLWHA in England and especially in the East Midlands are scarce. Despite the presence of emblematic organisations in the UK such as THT or UK Positive Nation, these types of PSO are fairly scarce in Britain. Most of the groups are ‘offered’ by the NHS as an extra health support; therefore, the concept of peer support is not entirely part of these drop-in groups. This reduced the possibility for studying the effects of peer support strategies used by PLWHA for PLWHA as described in this PhD project. This fact also reduced the number of participants possible for recruitment in England.

The low number of PSO in England is interpreted as related to one of the outcomes of this research: the high level of discrimination PLWHA suffer in England and the wish to keep their diagnosis secret. Consequently, people may be unwilling to join these kinds of groups (or start them) because this membership may involve disclosure of one's HIV diagnosis. These may open a significant area of research about parallel effects of discrimination in terms of how open PLHWA are to using cooperative strategies for the

self-provision of social support. Additionally, in England, the support provided by the NHS covers the basic needs of support and may discourage the creation of peer groups of support of PLWHA. A possible way to reach an increased number of participants from PSO in the UK may include recruit participants from different cities where—for instance—THT or another PSO has services. This way, more geographic locations may increase the number of participants willing to take part in the research. Another way to increase the sample may necessitate diversifying the places where PLWHA are recruited and including individuals from NHS services; this last option may involve NHS Ethical Committee approval prior to beginning work with patients and a redefinition of the concept of peer support.

Another factor to consider is “on-line” support groups. Participants may feel safer taking part in these groups and studies because, since there is not face-to-face interaction with any other member or researcher, they do not necessarily involve direct disclosure of diagnosis. Again, this implies a redefinition of what will be understood as peer support and peer support organisations. This also implies necessary consideration of the sort of support offered by the site and sought out by the “surfers”. As described by Lin (2009), self-efficacy and online support expectancy are key factors when using online sources. Additionally, the network size and the usage of information technology influence online social support. As discussed by Mo (2010), different levels of participation in these online groups involve different levels of empowerment. Participants who post regularly in these groups (higher participation) receive higher social support and information in the empowerment process and report higher satisfaction from their relationship with the group compared to participants who only read posts (“lurkers”). Lurking is the most common form of participation. This offers

an interesting but radically different source for and method of support that does not necessarily involve peer support strategy.

2) A progressive drop out was experienced during the pilot application of the Intervention Programme. The length of the Intervention Programme (13 sessions) was mentioned by the participants as an obstacle to adherence. Additionally, a later analysis partially explained this drop out, situating lower adherence among participants with higher psychological symptoms and lower CD4+ counts; the number of attended sessions was positively correlated with perception of social support and negatively with anxiety and depression. A similar situation was observed in Chile (described in Chapter Six); using the data from the first evaluation, higher incidence of depression and major use of avoidance was found among participants who responded at the first but not the second evaluation, correlating adherence with the absence of psychological symptoms. Additionally, the mean of CD4+ counts among those responding at the second evaluation was high compared with the mean of the participants responding the first evaluation, indicating that participants with higher CD4+ counts were more adherent compared with participants with lower CD4+ counts. These data link participant drop out with psychological and immunological status; participants with fewer psychological afflictions are more likely to remain adherent to this kind of intervention. These findings are consistent with Greenson's (2008) conclusions; a psychoimmune model was tested over a sample of 200 PLWHA accounting for 67% of the variation of HIV disease severity, suggesting that distress-related alterations in lymphocytes' immunity may play a role in bio-behavioural mechanism in HIV/AIDS. Therefore, and based on the results of the present PhD study, it is possible that higher CD4+ counts may also be used as a predictive factor for adherence. Further research may study in detail

these relationships and establish the validity of this contribution to the literature; baseline data can be used as a predictor of treatment adherence and as a guide to avoid participant drop-out.

As a consequence a reduced number of participants in both countries (Chile and England) and, for the purposes of the study, from two non-comparable groups (members and non-members of PSO of PLWHA) were obtained, reducing the power in statistical calculation. Despite this drop-out, significant correlations were found among the variables in PLWHA in England (Chapter Seven) and a case report with remarkable results was presented in Chapter Eight. In Chile the solution decided upon was the use of the first two evaluation points, which had the highest number of participants compared with the other evaluations. All the results were extracted from these two-evaluation studies.

Future studies or application of the Intervention Programme might consider taking specific actions to prevent participant drop-out, perhaps focusing on participants showing higher symptoms of depression, anxiety or perceived lack of social support at the baseline evaluation. These actions may include an interim period between the baseline evaluation and the intervention in order to review the psychological results before the intervention began; if necessary, then, part of the first session could be addressed to the importance of adherence and to identifying the avoidance of social contact commonly part of depression or stress. Another action might include changes in the order of the topics of the intervention itself; for instance, if higher levels of anxiety are observed among participants, that topic would be the best starting point.

9.5. Final considerations

This research, based on the reviewed literature and the outcomes of the studies described across the previous Chapters, proposes HIV/AIDS as a complex immunological and psycho-social process of living with a chronic disease (chronic disease for the countries where full HAART is provided). Environmental factors such as social stigma and discrimination against PLWHA increase external sources of stress and are connected with depressive and avoidance behaviours, severely affecting received and perceived social support, which was found to be strongly connected with people's general health. This transforms HIV/AIDS into a health status with unique characteristics, basically related to being a stigmatised sexual disease. In response, PLWHA have been using cooperative strategies such as PSOs which aim to reduce discrimination, lack of understanding and self-provide social support.

Despite all this, and according the results of this research, the effects on general health of PSO of PLWHA using peer support as a primary strategy have been underused; in addition, these effects have not been studied. PSO were linked with important benefits on general (immunological and psychological) health for PLWHA members of these organisations. Additionally, socio-cultural characteristics were described as an important factor influencing the provision and perception of social support, the approaches and strategies employed to support PLWHA, and the structure and targets of PSO and health services. PSS, individuals' perception of needs satisfaction, self-actualisation and immunological parameters are proposed to have a strong and direct correlation; however, this novel approach to social support theory needs further research to analyse the extent of this interaction.

The study of PLWHA, healthcare teams and PSO of PLWHA in Chile, Romania and England provided not only the option of a trans-cultural analysis, but also the chance to study the process of living with HIV/AIDS by working directly with all the most important key actors of this dynamic. This enriched the quality and quantity of the resulting data and increased the understanding of this dynamic; it defined the entire research process and will guide future applications of the Psychosocial Intervention Programme. Based on this understanding, this PhD research process enables the researcher to undertake, under improved conditions, further approaches to study the process of living with HIV/AIDS and people living with the virus. These studies will include novel factors such as the influence of cultural contexts and characteristics, the role of peer support groups, the impact of PNI-based interventions, and the utilisation of the “living together” strategy with the goal of the self-provision of social support. This valuable experience allows the perception of the PhD research as a significant preparation process by which the student who completed it has become a better researcher.

Appendices

Appendix A: CDC Classification system: Category B symptomatic conditions

Appendix A: CDC Classification system category B

Category B symptomatic conditions are defined as symptomatic conditions occurring in an HIV-infected adolescent or adult that meet at least 1 of the following criteria:
a) They are attributed to HIV infection or indicate a defect in cell-mediated immunity.
b) They are considered to have a clinical course or management that is complicated by HIV infection.
Examples include, but are not limited to, the following:

- Bacillary angiomatosis
- Oropharyngeal candidiasis (thrush)
- Vulvovaginal candidiasis, persistent or resistant
- Pelvic inflammatory disease (PID)
- Cervical dysplasia (moderate or severe)/cervical carcinoma in situ
- Hairy leukoplakia, oral
- Idiopathic thrombocytopenic purpura
- Constitutional symptoms, such as fever (>38.5°C) or diarrhea lasting >1 month
- Peripheral neuropathy
- Herpes zoster (shingles), involving ≥2 episodes or ≥1 dermatome

Source: HIV Classification: CDC and WHO Staging Systems
http://www.aidsetc.org/aidsetc?page=cm-105_disease#S6X

Appendix B: CDC Classification system: Category C AIDS-indicator conditions

CDC Classification system category C

Bacterial pneumonia, recurrent (≥2 episodes in 12 months)
Candidiasis of the bronchi, trachea, or lungs
Candidiasis, esophageal
Cervical carcinoma, invasive, confirmed by biopsy
Coccidioidomycosis, disseminated or extrapulmonary
Cryptococcosis, extrapulmonary
Cryptosporidiosis, chronic intestinal (>1-month duration)
Cytomegalovirus disease (other than liver, spleen, or nodes)
Encephalopathy, HIV-related
Herpes simplex: chronic ulcers (>1-month duration), or bronchitis, pneumonitis, or esophagitis
Histoplasmosis, disseminated or extrapulmonary
Isosporiasis, chronic intestinal (>1-month duration)
Kaposi sarcoma
Lymphoma, Burkitt, immunoblastic, or primary central nervous system
Mycobacterium avium complex (MAC) or M kansasii , disseminated or extrapulmonary
Mycobacterium tuberculosis , pulmonary or extrapulmonary
Mycobacterium , other species or unidentified species, disseminated or extrapulmonary
Pneumocystis jiroveci (formerly carinii) pneumonia (PCP)
Progressive multifocal leukoencephalopathy (PML)
Salmonella septicemia, recurrent (nontyphoid)
Toxoplasmosis of brain
Wasting syndrome due to HIV (involuntary weight loss >10% of baseline body weight) associated with either chronic diarrhea (≥2 loose stools per day ≥1 month) or chronic weakness and documented fever ≥1 month

Source: HIV Classification: CDC and WHO Staging Systems
http://www.aidsetc.org/aidsetc?page=cm-105_disease#S6X

Appendix C: Stages of the natural evolution of the HIV infection

- **The primary HIV infection phase** (acute retroviral syndrome). This stage appears during the first and the sixth week of the sero-conversion. The sero-conversion refers the process when the virus starts to replicate itself, as a result viral proteins start to circulate in the blood, this will allow the detection tests, such as ELISA, to pass from negative to positive in the serologic analysis. This stage may include the first symptoms of the acquisition: fever, arash, adenopathies and pharyngitis. These symptoms are presented in different levels from no symptoms to critical states for 50% to 90% of the people. CD8+ lymphocytes increase in numbers, CD4+ decrease and there is a rapid increase of virus level.
- **The asymptomatic infection** (or clinical latency) is from the sero-conversion to the first illness manifestations. The length of this stage is variable, from months to years. The normal period is between 5 to 11 years and is affected, for example by the age at seroconversion and the acquisition path. During this period the virus continuously replicates itself and the number of CD4+ lymphocytes decrease in approximated rates of 50 cells/m^3 per year. Approximately 4 to 7% of the patients keep stable with high CD4+ counts, low viral load (VL) and without symptoms of infection for more than 11 years, all this without ARVT. On the other hand less than 5% progress extremely fast to the symptomatic stage in less than 2 years.
- **Early symptomatic infection** is the third stage, the CD4+ count falls bellow 500 cells/m^3, and symptoms of B stage appears (see appendix 1 for symptoms of each HIV sub-stage). The viral load (VL) progressively rises, the length of this stage is variable and if ARVT is not started to avoid the appearance of opportunistic diseases the progression to AIDS is fast.
- **AIDS**: defined by the appearance of opportunistic infections and/or the fall of CD4+ bellow 200 cells/m^3. The levels of VL are usually higher than 10^5 copies/m^3. If ARVT is not started survival is between 12 to 18 months. (Sepulveda, 2002).

Appendix D: Stages of HIV replication and antiretroviral action

1. Attachment: In order to get in contact with the host cell the virus need the presence of both the CD4+ receptor and the CCR5 or CXCR4 co-receptors.

2. Fusion: The CD4+ and CCR5 and CXCR4 works as the “entrance door” for the virus in the lymphocyte.

The *entry inhibitors* are drugs used to avoid the attachment and the fusion of the virus to the cell, these allocate them selves either on the virus proteins (the gp120) or the lymphocyte receptor (CD4+) of co-receptors (CCR5 or CXCR4) blocking the “entrance door”.

3. Reverse transcription: Once inside this retrovirus uses the *inverse transcriptase* to transform the genomic RNA information into pro-viral deoxyribonucleic acid (DNA).

The *reverse transcriptase inhibitors nucleolus analogues or no-analogues* are used to prevent the virus transform its RNA to DNA. To do this the *reverse transcriptase inhibitors* locates itself at the end of the genetic chain (analogues) or somewhere in the middle of the genetic chain (no-analogues) the genetic chain. This impedes the connection with the genetic material of the host cell.

4. Once transcribed the *integrase* allows the pro-viral DNA to integrate into the lymphocyte DNA and in this way it is able to replicate itself using the structure of the lymphocyte.

The *integrase inhibitors* impede the pro-viral DNA entering the lymphocyte DNA by blocking the integrase.

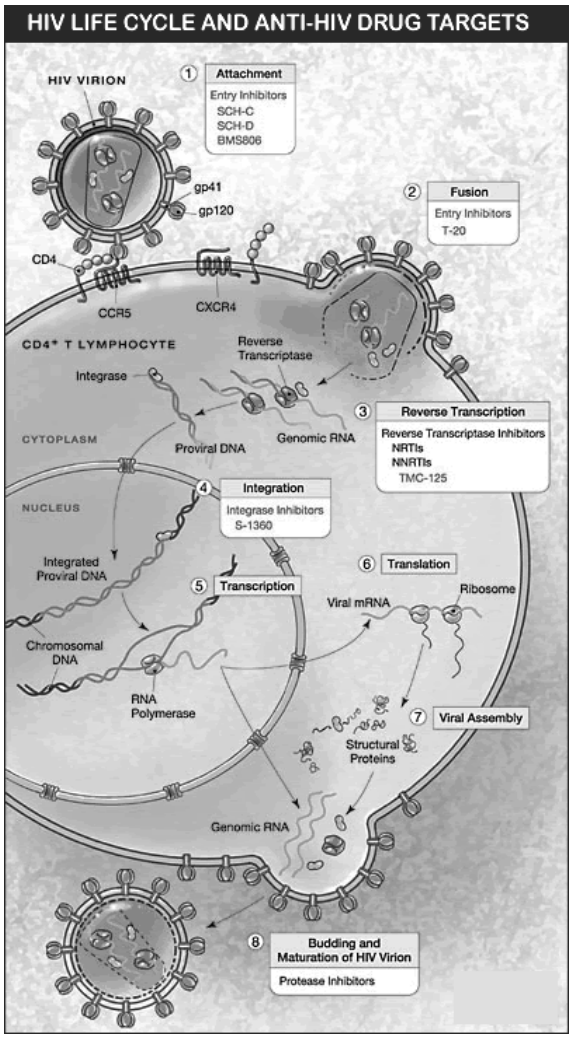
5. Transcription: the integrated pro-viral DNA copied is transformed into RNA polymerase and genomic RNA making it possible for the virus to re-assembe.

6. Translation: all the replicated viral structures are “brought together” as mRNA.

7. Viral Assembling: structural proteins re-assembling the virus as genomic RNA to prepare it to leave the lymphocyte.

8. Budding and maturation of the virion: the protease enables the virus to mature and able to break the plasmatic membrane of the lymphocytes to exit the cell.

To either avoid the maturing process of the virus or to impede a mature virus exiting the lymphocyte and infecting more cells, the *protease inhibitors* are used.



VIH Life Cycle and Anti-HIV drugs Targets.
Source: GlaxoSmithKline

Appendix E: Ethical approval from Nottingham University Research and Ethical Committee.

The University of Nottingham

Our reference:
RIS 31926
Your reference:
08/H0403/71

Research Innovation Services
University of Nottingham
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Lenton Lane Nottingham
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Nottingham REC 1
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Nottingham
NG1 6GN

Mr Aaron Cortes, Chief Investigator
University of Nottingham
Institute of Work, Health and Organisation
8 William Lee Building
Science and Technology Park
Nottingham
NG7 2RQ

20th May 2008

Dear sir or madam,

Sponsorship Statement

Re: Psychoneuroimmunology: Social Support Perception and Health Significance in HIV.

I can confirm that this research proposal has been discussed with the Chief Investigator and agreement to sponsor the research is in place.

An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.*

Any necessary indemnity or insurance arrangements will be in place before this research starts. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.

Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.

The duties of sponsors set out in the NHS Research Governance Framework for Health and Social Care will be undertaken in relation to this research.**

* Not applicable to student research (except doctoral research).
** Not applicable to research outside the scope of the Research Governance Framework.

Yours faithfully

Paul Cartledge
Head of Research Grants and Contracts
University of Nottingham

world-changing research from The University of Nottingham

Date: 20/05/2008 (dd/mm/yyyy)

Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co-sponsors by a representative of the sponsor nominated to take the lead for the REC application.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.
2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.*
3. Any necessary indemnity or insurance arrangements, as described in question A35, will be in place before this research starts.
4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.
5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.
6. The duties of sponsors set out in the NHS Research Governance Framework for Health and Social Care will be undertaken in relation to this research.**
7. I understand that the lay summary of this study will be published on the website of the National Research Ethics Service (NRES) as it appears in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

* Not applicable to student research (except doctoral research).
** Not applicable to research outside the scope of the Research Governance Framework.

Signature: .....

Print Name: Prof Paul Cartledge

Post: Head of Research Operations

Organisation: University of Nottingham

Date: 20/05/2008 (dd/mm/yyyy)

Appendix F: Perceived Support Questionnaire – Original Spanish version.

CUESTIONARIO; PERCEPCIÓN DEL APOYO SOCIAL EN LAS RELACIONES INTERPERSONALES

Aarón Aranís Cortés Rojas (2002).

- PRIMERA PARTE; PREGUNTAS

1. En los últimos tres meses ¿A cuantos grupos sociales o de pares has pertenecido?
   1____ 2a 4 ____ 5 a 7____ más de 7 ____

2. ¿A qué área pertenecen los grupos sociales de los que eres parte?
   __ De estudio __ Cercanas al domicilio
   __ De trabajo __ Asociación política
   __ Agrupación religiosa __Agrupaciones de PVVIH
   __ Familiar __ Otra(s) (nombrar)

3. ¿Sientes que aportas a tu grupo de amigos y que tu presencia en el es importante?
   Sí ____ No ___

4. ¿Sientes que los otros miembros del grupo están comprometidos con lo que le suceda a este?
   Sí ____ No ____

5. ¿A qué grupos, de los que perteneces te consideras más cercano?
   _____ De estudio _____ Cercanas al domicilio
   _____ De trabajo _____ Asociación política
   _____ Agrupación religiosa _____ Agrupaciones de PVVIH
   _____ Familiar _____ Otra(s) (nombrar)

6. ¿Crees que tus amigos realizan esfuerzos -o los harían si fuese necesario- para la mantención del grupo?
   Sí____ No ____

7. ¿Qué tan regularmente te reúnes con el (los) grupo de amigos más cercanos?
   __ una vez al mes __ dos o tres veces al mes
   __ una vez por semana __ dos o más veces por semana
   __ todos los días

8. ¿Qué tan importante es tu contribución al grupo de amigos más cercano?
   __ Muy importante __ Más importante que el promedio __ Igual que la mayoría
   __ Menos importante que la mayoría __ No muy importante

9. ¿Cuántas personas componen aproximadamente el grupo de amigos más cercano? Ubica tu respuesta frente a la categoría que corresponda
   _____ De estudio _____ Cercanas al domicilio
   _____ De trabajo _____ Asociación política
   _____ Agrupación religiosa _____ Agrupaciones de PVVIH
   _____ Familiar _____ Otra(s) (nombrar)

- SEGUNDA PARTE; AFIRMACIONES

10. Mi grupo de amigos (el más cercano) tiene características que le dan una identidad propia.
___Muy de acuerdo ___Medianamente en desacuerdo
___Medianamente de acuerdo ___Muy en desacuerdo

11. Puedo expresar mis opiniones libremente frente a mi grupo de amigos
___Muy de acuerdo ___Medianamente en desacuerdo
___Medianamente de acuerdo ___Muy en desacuerdo

12. Me siento suficientemente escuchado por mis amigos.
___Muy de acuerdo ___Medianamente en desacuerdo
___Medianamente de acuerdo ___Muy en desacuerdo

13. Me siento acogido en mi familia.
___Muy de acuerdo ___Medianamente en desacuerdo
___Medianamente de acuerdo ___Muy en desacuerdo

14. Mis amigos pueden darme buenos consejos para mi desarrollo personal.
___Muy de acuerdo ___Medianamente en desacuerdo
___Medianamente de acuerdo ___Muy en desacuerdo

15. El pertenecer a un grupo de amigos me permite conocer más de mí.
___Muy de acuerdo ___Medianamente en desacuerdo
___Medianamente de acuerdo ___Muy en desacuerdo

16. Creo que mis amigos me aportan posibilidades de crecer.
___Muy de acuerdo ___Medianamente en desacuerdo
___Medianamente de acuerdo ___Muy en desacuerdo

17. Me siento representado por la identidad de mi grupo.
___Muy de acuerdo ___Medianamente en desacuerdo
___Medianamente de acuerdo ___Muy en desacuerdo

18. Si quiero conversar con alguien puedo recurrir a alguno de ellos y me escuchará.
___Muy de acuerdo ___Medianamente en desacuerdo
___Medianamente de acuerdo ___Muy en desacuerdo

19. La mayoría de las veces, las soluciones que encontramos, tienen buenos resultados.
___Muy de acuerdo ___Medianamente en desacuerdo
___Medianamente de acuerdo ___Muy en desacuerdo

20. Si tengo problemas mis amigos podrán ayudarme.
___Muy de acuerdo ___Medianamente en desacuerdo
___Medianamente de acuerdo ___Muy en desacuerdo

21. Mi familia me apoya en lo que emprenda, si creo que es para mi bienestar
___Muy de acuerdo ___Medianamente en desacuerdo
___Medianamente de acuerdo ___Muy en desacuerdo

22. Con mis amigos resolvemos rápidamente los conflictos que se da en el grupo
___Muy de acuerdo ___Medianamente en desacuerdo
___Medianamente de acuerdo ___Muy en desacuerdo

23. Mis amigos han sido capaces de entregar afecto cuando lo he requerido.
___Muy de acuerdo ___Medianamente en desacuerdo
___Medianamente de acuerdo ___Muy en desacuerdo

Appendix G: One way ANOVA and Post Hoc test for the three evaluation moments of the CPAS validation

Test of Homogeneity of Variances

Perceived Support

Levene Statistic	df1	df2	Sig.
.545	2	267	.581

ANOVA

Perceived Support

	Sum of Squares	Df	Mean Square	F	Sig.
Between Groups	82.230	2	41.115	1.157	.316
Within Groups	9490.733	267	35.546		
Total	9572.963	269			

Multiple Comparisons

Perceived Support

Tukey HSD

(I) Group	(J) Group	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
Sample 1 I-WHO	Sample 2 I-WHO	-.09664	2.151	.999	-5.1680	4.9747
	Sample 3 Uni	1.68668	1.496	.498	-1.8405	5.2138
Sample 2 I-WHO	Sample 1 I-WHO	.09664	2.151	.999	-4.9747	5.1680
	Sample 3 Uni	1.78332	1.639	.522	-2.0806	5.6472
Sample 3 Uni	Sample 1 I-WHO	-1.68668	1.496	.498	-5.2138	1.8405
	Sample 2 I-WHO	-1.78332	1.639	.522	-5.6472	2.0806

Appendix H: Pearson correlations between CPAS Section Two and Section Three

Pearson correlations between CPAS Section Two and Section Three				
	How many groups	The closest group	How often communicate?	Perceived Support
How many groups	1	.191**	.082	.200**
		.002	.177	.001
	275	258	275	270
The closest group	.191**	1	.159*	.231**
	.002		.011	.000
	258	258	258	253
How often communicate?	.082	.159*	1	.347**
	.177	.011		.000
	275	258	275	270
Perceived Support	.200**	.231**	.347**	1
	.001	.000	.000	
	270	253	270	270

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Appendix I: CPAS 16-items – English version

PAS: QUESTIONNAIRE OF PERCEIVED SOCIAL SUPPORT
Aaron Cortes PhD candidate - Applied Psychology

SECTION ONE

a) Initials:
b) Age:
c) Sex:

SECTION TWO

1. What areas do your social networks or groups belong to? (select all of them)
   __ Study
   __ Work
   __ Church/religious
   __ Family
   __ Partner
   __ Friends in general
   __ Social group
   __ Other(s) specify:
   _____
   __ None

2. To which group, of those to which you belong, do you feel closest? (Select just one)
   __ Study
   __ Work
   __ Church/religious
   __ Family
   __ Partner
   __ Friends in general
   __ Social group
   __ Other(s) specify:
   _____
   __ None

3. How often do you usually communicate with the group you selected as closest in question 2?
   __ Once a week or more
   __ Once a month or less
   __ Twice a year or less

SECCTION TWO

4. My closest group of friends has characteristics that provide its own identity.
   __ Strongly agree
   __ Agree
   __ Neither agree nor disagree
   __ Disagree
   __ Strongly disagree

5. I can freely express my opinion to my partner or group of friends.
   __ Strongly agree
   __ Agree
   __ Neither agree nor disagree
   __ Disagree
   __ Strongly disagree

6. I feel I can count on my closest friends or partner when I need to be listened to.
   __ Strongly agree
   __ Agree
   __ Neither agree nor disagree
   __ Disagree
   __ Strongly disagree

7. I feel emotionally sheltered by my family.
   __ Strongly agree
   __ Agree
   __ Neither agree nor disagree
   __ Disagree
   __ Strongly disagree
8. If I ask for it, my friends can give me good advice for my personal development.
   __ Strongly agree
   __ Agree
   __ Neither agree nor disagree
   __ Disagree
   __ Strongly disagree

9. To be part of a group of friends allows me to know myself better.
   __ Strongly agree
   __ Agree
   __ Neither agree nor disagree
   __ Disagree
   __ Strongly disagree

10. I think that my friends give me possibilities for growth.
   __ Strongly agree
   __ Agree
   __ Neither agree nor disagree
   __ Disagree
   __ Strongly disagree

11. If I want to talk to somebody, I can turn to a friend/or my partner and he/she will listen to me.
   __ Strongly agree
   __ Agree
   __ Neither agree nor disagree
   __ Disagree
   __ Strongly disagree

12. Most of the time, solutions to problems presented by my group of friends are useful.
   __ Strongly agree
   __ Agree
   __ Neither agree nor disagree
   __ Disagree
   __ Strongly disagree

13. If I have problems my friend/partner would help me.
   __ Strongly agree
   __ Agree
   __ Neither agree nor disagree
   __ Disagree
   __ Strongly disagree

14. If something is for my own good, my family will support me.
   __ Strongly agree
   __ Agree
   __ Neither agree nor disagree
   __ Disagree
   __ Strongly disagree

15. Among my friends conflicts are promptly resolved.
   __ Strongly agree
   __ Agree
   __ Neither agree nor disagree
   __ Disagree
   __ Strongly disagree

16. My friends have been able to give me affection when I have needed it.
   __ Strongly agree
   __ Agree
   __ Neither agree nor disagree
   __ Disagree
   __ Strongly disagree

Appendix J: Informed consent - Chile

FORMULARIO DE CONSENTIMIENTO INFORMADO

INVESTIGADOR RESPONSABLE: PS. Aarón Cortes
Cursando 2º año de Doctorado en Psicología de la Salud,
I-WHO University of Nottingham, Inglaterra.
Psicólogo Sección Inmunología, Hospital Clínico Universidad de Chile
E-mail: aacortes@redclinicauchile.cl

TITULO DEL PROYECTO: Psiconeuroinmunología; valor de la percepción del apoyo social en el funcionamiento inmunológico de personas viviendo con VIH/SIDA.

Se me ha solicitado participar en un proyecto de investigación que está estudiando **la relación entre la percepción del apoyo social y el funcionamiento inmunológico**. Al participar en este estudio, yo estoy de acuerdo en **completar cuestionarios psicológicos y facilitar mis resultados de Carga Viral y de recuento de linfocitos CD4+**, los cuales me realizo periódicamente como parte de mis exámenes rutinarios.

Yo entiendo que:

a) La presente investigación no implica riesgos para mi salud.

b) Los tratamientos alternativos incluyen una atención integral que incluye mis propios recursos sociales enfrentando el VIH desde una mirada más amplia que incluye la atención clínica, psicológica y social.

c) Los posibles beneficios que obtendré en este estudio son: evaluaciones periódicas de mis estados de depresión y estrés, conocimiento de mis redes sociales de apoyo y conocer cuan favorables pueden ser los grupos de ayuda entre pares.

d) Cualquier pregunta que yo quiera hacer con relación a mi participación en este estudio deberá ser contestada por Ps. Aarón Cortés Rojas, psicólogo sección inmunología.

e) Yo podré retirarme de este estudio en cualquier momento sin ser obligada/o a dar razones y sin que esto me perjudique en mi calidad de paciente o usuaria del Hospital Clínico de la Universidad de Chile u otro recinto Hospitalario.

f) Los resultados de este estudio pueden ser publicados, pero mi nombre o identidad no será revelado y mis datos clínicos y experimentales permanecerán en forma confidencial, a menos que mi identidad sea solicitada por ley.

g) Mi consentimiento está dado voluntariamente sin que haya sido forzada/o u obligada/o.

INVESTIGADOR PRINCIPAL O MEDICO RESPONSABLE — NOMBRE/CÓDIGO Y RUT DEL PACIENTE

FECHA ……

Appendix K: Patient information Sheet – Chile

Psiconeuroinmunología: Percepción del Apoyo Social y su significación en Salud en VIH/SIDA
Hoja de Información para el Participante

¿Cuál es el propósito del estudio?
Evaluar los niveles de percepción del apoyo social, ansiedad, depresión y resiliencia entre personas viviendo con VIH/SIDA y comparar estos niveles con su funcionamiento inmunológico. Este estudio es parte una Investigación Doctoral de la Universidad de Nottingham, Inglaterra, en colaboración con el Hospital de la Universidad de Chile y VIVO POSITIVO, financiada por el Gobierno de Chile.

¿Qué se me pedirá si decido tomar parte del estudio?
Sólo deberás completar datos personales –los que no incluyen tu nombre- y contestar tests psicológicos una vez cada 3 meses por un período de un año, esto implica 5 aplicaciones, las cuales tomarán entre 20 a 30 minutos cada una.
Tu recibirás los resultados de tus test dentro de las siguientes semanas a tu respuesta, de este modo sabrás de tu estado psicológico y su relación con tu funcionamiento orgánico.

¿Existe algún riesgo si tomo parte en este estudio?
Dado que el estudio sólo consiste en aplicación de test psicológicos no reviste ningún riesgo para tu salud, además se tomarán todas las medidas de seguridad para que tu identidad se mantenga bajo estricta confidencialidad.

¿Cuáles son los posibles beneficios al tomar parte en el estudio?
De tomar parte en la evaluación, recibirás periódicamente evaluaciones psicológicas y un informe de tu estado, el cual te llegará vía e-mail al cabo de unas semanas de que respondas los tests, podrás hacer un seguimiento de tu evolución en niveles de depresión, ansiedad por estrés y apoyo social por un período de un año y además ligarlo con tu funcionamiento inmunológico, además al final del proyecto recibirás un resumen de todo tu proceso en el estudio.

Confidencialidad: ¿Quién sabrá que estoy tomando parte de este estudio?
Sólo el equipo de investigadores (Ps. Aarón Cortés y Dr. Nigel Hunt) tendrán acceso a información directa de datos de participantes, en toda información extra o publicable no se incluirán datos que pudiesen identificar a personas individuales.

¿Qué pasará con los resultados de la investigación?
Además de los informes individuales periódicos que recibirás, los resultados generales serán publicados en revistas científicas internacionales. Copias de dichas publicaciones y/o el resumen de la investigación será enviado a la institución a través de la cual fuiste contactado.

¿Qué pasa ahora?
Si quieres participar en la investigación contesta los test que encontrarás en los archivos adjuntos, los cuales toman aproximadamente 25 minutos para completarlos. Descarga los archivos cópialos en tu PC y, una vez los hayas respondido, guárdalos y adjúntalos en un nuevo e-mail dirigido al investigador principal Ps. Aarón Cortés aacortes@redclinicauchile.cl o lwxaac@nottingham.ac.uk. Si necesitas mayores antecedentes para tomar la decisión de participar o no, no dudes en escribir a los mismos e-mails y tus dudas respecto al proyecto serán aclaradas a la brevedad.

Appendix L: Informed consent - UK

CONSENT FORM

Title of Study: Psychoneuroimmunology: Social Support Perception and Health Significance in HIV/AIDS

Name of Researcher: Aaron Cortes

Name of Participant: **Please initial box**

1. I confirm that I have read and understand the information sheet version 1.0, dated on 7th May 2008 for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐

3. I understand that my CD4+ lymphocytes and Viral Load Level results may be made available to the research group where it is relevant to my taking part in this study. I give permission for these individuals to have access to my records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐

4. I understand and agree that psychological questionnaires will be applied for analysis of my levels of depression, anxiety, coping and social support perception. ☐

5. I agree to take part in the above study. ☐

_____	_____	_____
Name of Participant	**Date**	**Signature**
_____	_____	_____
Name of Person taking consent (if different from Principal Investigator)	Date	Signature
Aaron Cortés	_____	_____
Name of Principal Investigator	Date	Signature

3 copies: 1 for participant, 1 for the project notes and 1 for the medical notes

Appendix M: Psychosocial Intervention Programme Table of content: English 13-session version.

"Psychosocial Intervention Programme for PLHIV/AIDS"
Psychol. Aaron Cortes PhD Student - Applied Psychology
University of Nottingham

Base line	Psychosocial Assessment
	Social Support Perception, Anxiety by Stress and Depression.

Session	Variable: Depression			
1	Presentation	Depression: Basic information	What is depression?	What causes depression?
2	Depression and behaviour			
3	Depression		How to cope with it. Conflict solution	
4	Depression		Feelings involved	
5	Depression	Plan	Tips and applications	

Session	Variable: Anxiety			
6	Anxiety: Basic information	What is stress?	What causes anxiety	Effects Treatments
7	Body reaction to stress		Relaxation	
8	Interpretation of situations		Coping with anxiety Breath Techniques	
9	Applications	Relaxation	Plan	

Session	Variable: Perceived Social Support (PSS)			
10	PSS: Basic Information	What is PSS?	How PSS works?	
11	Groups and identity		Free association	Confidence play
12	Discussion: how to improve social support		Relaxation	
13	Confidence play	Discussion	Feedback	Farewell

AIM

The main objective is provide participants with different knowledge in order to face better stressful situations, potentially depressive events and perceptions which may limit social support.

Through the utilisation of the most useful techniques regarding personal needs and characteristics, participants are expected to be able to re-interpret their own life situations to achieve better results and reducing interpretations causing conflicts or limiting their abilities.

Appendix N: Mann-Whitney test women and men experimental groups and control group comparisons: First and second evaluations.

N.1. Women and men group comparison
N.2. Control and men group comparison
N.3. Control and women group comparison

Appendix N.1 - Mann-Whitney: Men - Women groups comparison

	CD4+	Years in PSO	N of Sessions	PSS	
Evaluation	**Baseline**	**Baseline**	**2nd**	**1st**	**2nd**
Mann-Whitney U	1	2	3	3	4
Z	-1.528	-1.742	-1.461	-1.443	-0.714
Exact Sig. [2*(1-tailed Sig.)]	.200	.114	.200	.200	.629

	HAD-Anxiety		HAD-Depression		FDC-Approach	
Evaluation	**1st**	**2nd**	**1st**	**2nd**	**1st**	**2nd**
Mann-Whitney U	6	5	2	4	3.5	5.5
Z	-0.588	-0.354	-1.742	-0.707	-1.307	-0.178
Exact Sig. [2*(1-tailed Sig.)]	.686	.857	.114	.629	.200	.857

	FDC-Avoidance		FDC Emot Regul		FDC-Reappraisal	
Evaluation	**1st**	**2nd**	**1st**	**2nd**	**1st**	**2nd**
Mann-Whitney U	2.5	1.5	6	6	5.5	6
Z	-1.597	-1.62	-0.584	0	-0.726	0
Exact Sig. [2*(1-tailed Sig.)]	.114	.114	.686	1.000	.486	1.000

Appendix N.2 - Mann-Whitney: Control - Men groups comparison

	CD4+	Years in PSO	PSS		HAD-Anxiety	
Evaluation	**Baseline**	**Baseline**	**1st**	**2nd**	**1st**	**2nd**
Mann-Whitney U	2.000	3.000	2.000	2.000	5.000	4.000
Z	-1.414	-1.461	-1.753	-1.732	-.866	-1.155
Exact Sig. [2*(1-tailed Sig.)]	.229	.200	.114	.114	.486	.343

	HAD-Depression		FDC-Approach		FDC-Avoidance	
Evaluation	**1st**	**2nd**	**1st**	**2nd**	**1st**	**2nd**
Mann-Whitney U	5.000	4.000	3.500	7.000	**.000**	**.500**
Z	-.866	-1.169	-.892	-.292	**-2.121**	**-2.191**
Exact Sig. [2*(1-tailed Sig.)]	.486	.343	.400	.886	**.057**	**.029**

	FDC-Emotional Regulation		FDC-Reappraisal	
Evaluation	**1st**	**2nd**	**1st**	**2nd**
Mann-Whitney U	5.500	8.000	3.000	5.500
Z	-.178	.000	-1.061	-.726
Exact Sig. [2*(1-tailed Sig.)]	.857	1.000	.400	.486

Appendix N.3 - Mann-Whitney: Control - Women groups comparison

	CD4+	Years in PSO	PSS		HAD-Anxiety	
Evaluation	**Baseline**	**Baseline**	**1st**	**2nd**	**1st**	**2nd**
Mann-Whitney U	1.000	**1.000**	7.000	6.000	5.000	5.000
Z	-1.768	**-2.033**	-.289	.000	-.871	-.354
Exact Sig. [2*(1-tailed Sig.)]	.114[a]	**.057**	.886	1.000	.486	.857

	HAD-Depression		FDC-Approach		FDC-Avoidance	
Evaluation	**1st**	**2nd**	**1st**	**2nd**	**1st**	**2nd**
Mann-Whitney U	8.000	6.000	6.000	5.500	4.000	2.000
Z	.000	.000	.000	-.178	-.707	-1.414
Exact Sig. [2*(1-tailed Sig.)]	1.000	1.000	1.000	.857	.629	.229

	FDC-Emotional Regulation		FDC-Reappraisal	
Evaluation	**1st**	**2nd**	**1st**	**2nd**
Mann-Whitney U	4.500	5.500	6.000	5.500
Z	-.535	-.178	.000	-.178
Exact Sig. [2*(1-tailed Sig.)]	.629	.857	1.000	.857

Appendix O: Kruskal Wallis Test. Control and experimental group comparisons within and between evaluations.

Appendix O- Kruskal-Wallis: Baseline & second Ev of PLWHA: Control and experimental group comparison

	CD4+	Years in PSO	PSS		HAD Anxiety		HAD-Depression	
Evaluation	Baseline	Baseline	1st	2nd	1st	2nd	1st	2nd
Chi-Square	**4.845**	**6.102**	3.602	2.405	1.205	1.136	2.457	1.315
df	**2**	**2**	2	2	2	2	2	2
Asymp. Sig.	**0.089**	**0.047**	0.165	0.3	0.547	0.567	0.293	0.518
	FDC Approach		FDC Avoidance		FDC Emot Regul		FDC Reappraisal	
Evaluation	1st	2nd	1st	2nd	1st	2nd	1st	2nd
Chi-Square	1.779	0.089	**5.247**	**6.373**	0.459	0.013	1.107	0.357
df	2	2	**2**	**2**	2	2	2	2
Asymp. Sig.	0.411	0.957	**0.073**	**0.041**	0.795	0.993	0.575	0.836

Appendix P: Spearman correlations between demographic and clinical variables at baseline: Psychosocial Intervention Programme - Pilot application

P.1. Baseline Pilot - PSO: Spearman demographic-clinical-psychological data correlations

P.2. Second evaluation Pilot - PSO: Spearman demographic-clinical-psychological data correlations

Appendix P.1 - Baseline Pilot - PSO: Spearman demographic-clinical-psychological data correlations

		Sex	Age	Years in PSO	CD4+	N of Sessions
Sex	Correlation Coefficient	1.000	.269	.492	.284	-.552
	Sig. (2-tailed)	.	.397	.104	.426	.156
	N	12	12	12	10	8
Age	Correlation Coefficient		1.000	.098	.176	.133
	Sig. (2-tailed)		.	.761	.627	.754
	N		12	12	10	8
Years in PSO	Correlation Coefficient			1.000	.813**	-.115
	Sig. (2-tailed)			.	.004	.786
	N			12	10	8
CD4+	Correlation Coefficient				1.000	-.551
	Sig. (2-tailed)				.	.257
	N				10	6
N of Sessions	Correlation Coefficient					1.000
	Sig. (2-tailed)					.
	N					8
CPAS Perceived Social Support	Correlation Coefficient	-.197	.060	.333	.067	.988**
	Sig. (2-tailed)	.540	.854	.290	.854	.000
	N	12	12	12	10	8
HAD Anxiety	Correlation Coefficient	.025	-.327	-.486	-.238	-.859**
	Sig. (2-tailed)	.939	.300	.109	.508	.006
	N	12	12	12	10	8
HAD Depression	Correlation Coefficient	.222	.092	-.336	-.067	-.958**
	Sig. (2-tailed)	.488	.777	.285	.853	.000
	N	12	12	12	10	8
FDC Approach	Correlation Coefficient	.058	.648*	.209	.420	-.067
	Sig. (2-tailed)	.865	.031	.537	.260	.875
	N	11	11	11	9	8
FDC Avoidance	Correlation Coefficient	-.318	-.009	-.330	-.417	.509
	Sig. (2-tailed)	.340	.979	.321	.265	.198
	N	11	11	11	9	8

FDC Emotional Regulation	Correlation Coefficient	-.058	.725*	.076	.354	-.073
	Sig. (2-tailed)	.865	.012	.824	.349	.863
	N	11	11	11	9	8
FDC Reappraisal	Correlation Coefficient	.029	.820**	-.002	.200	.067
	Sig. (2-tailed)	.933	.002	.995	.606	.875
	N	11	11	11	9	8

Appendix P.2 - Second evaluation Pilot - PSO: Spearman demographic-clinical-psychological data correlations

		Sex	Age	Years in PSO	CD4+	N of Sessions
CPAS Perceived Social Support	Correlation Coefficient	-.180	.059	.444	.109	.954**
	Sig. (2-tailed)	.597	.863	.171	.781	.001
	N	11	11	11	9	7
HAD Anxiety	Correlation Coefficient	.179	-.418	-.438	-.217	-.891**
	Sig. (2-tailed)	.598	.201	.177	.576	.007
	N	11	11	11	9	7
HAD Depression	Correlation Coefficient	.150	-.169	-.461	-.076	-.946**
	Sig. (2-tailed)	.660	.619	.154	.847	.001
	N	11	11	11	9	7
FDC Approach	Correlation Coefficient	-.211	**.523**	.235	.169	.615
	Sig. (2-tailed)	.533	**.099**	.487	.664	.142
	N	11	**11**	11	9	7
FDC Avoidance	Correlation Coefficient	-.211	-.476	.138	.269	-.093
	Sig. (2-tailed)	.534	.139	.686	.484	.843
	N	11	11	11	9	7
FDC Emotional Regulation	Correlation Coefficient	-.241	.824**	.147	.268	.435
	Sig. (2-tailed)	.476	.002	.666	.486	.329
	N	11	11	11	9	7
FDC Reappraisal	Correlation Coefficient	-.300	.466	.193	.294	.509
	Sig. (2-tailed)	.370	.149	.570	.442	.243
	N	11	11	11	9	7

* Demographic data (sex, age and years in PSO) did not vary from the baseline to the second evaluation (3 months); Clinical data (CD4+) was not available for the second evaluation. Therefore, these variables were not computed with each other for the second evaluation.

Appendix Q: Spearman correlations between psychological variables at baseline: Psychosocial Intervention Programme - Pilot application

Appendix Q.1 - Baseline Pilot - PSO: Spearman psychological data correlations

		PSS	Anxiety	Depress	Approach	Avoidance	Emot Regul	Reapp
CPAS PSS	r	1.000	-.887**	-.940**	.046	.398	.088	.162
	p	.	.000	.000	.893	.225	.798	.633
	n	12	12	12	11	11	11	11
HAD Anxiety	r		1.000	.835**	-.274	-.165	-.242	-.369
	p		.	.001	.416	.628	.472	.264
	n		12	12	11	11	11	11
HAD Depress	r			1.000	-.098	-.110	-.023	-.128
	p			.	.773	.748	.947	.708
	n			12	11	11	11	11
FDC Appr	r				1.000	-.341	.903**	.838**
	p				.	.305	.000	.001
	n				11	11	11	11
FDC Avoid	r					1.000	-.039	-.132
	p					.	.909	.698
	n					11	11	11
FDC Emot Regul	r						1.000	.878**
	p						.	.000
	n						11	11

Appendix Q.2 - Second evaluation Pilot - PSO: Spearman psychological data correlations

		PSS	Anxiety	Depress	Approach	Avoidance	Emot Regul	Reapp
CPAS PSS	r	1.000	-.861**	-.961**	.690*	.067	.339	.378
	p	.	.001	.000	.019	.846	.307	.252
	n	11	11	11	11	11	11	11
HAD Anxiety	r		1.000	.918**	-.858**	.174	-.650*	-.479
	p		.	.000	.001	.609	.030	.136
	n		11	11	11	11	11	11
HAD Depress	r			1.000	-.781**	.143	-.439	-.443
	p			.	.005	.676	.177	.173
	n			11	11	11	11	11
FDC Appr	r				1.000	-.450	.707*	.675*
	p				.	.165	.015	.023
	n				11	11	11	11
FDC Avoid	r					1.000	-.288	-.379
	p					.	.390	.250
	n					11	11	11
FDC Emot Regul	r						1.000	.743**
	p						.	.009
	n						11	11

Appendix R: Mann-Whitney test Years of membership and under ARVT influence over psychological and immunological variables.

R.1. Mann-Whitney: Years of membership and variables

R.2. Mann-Whitney: Years of ARVT intake and variables

Appendix R.1 - Mann-Whitney: Years of membership and variables

	Sex	Perceived Support		Anxiety		HAD-Depression		Approach	
Evaluation	1st	1st	2nd	1st	2nd	1st	2nd	1st	2nd
Mann-Whitney U	15	8.5	6.5	6	6	7	5	8	8
Z	-.561	-1.53	-1.56	-1.93	-1.64	-1.77	-1.83	-1.28	-1.29
Asymp. Sig. (2-tailed)	.575	.127	.120	.053	.100	.076	.067	.199	.197

	FDC-Avoidance		Emotional Regulation		Reappraisal		N of Sessions	CD4+
Evaluation	1st	2nd	1st	2nd	1st	2nd		
Mann-Whitney U	8	13.5	11	9.5	12.5	6.5	5	2.00
Z	-1.28	-.276	-.737	-1.01	-.457	-1.56	-.754	-2.19
Asymp. Sig. (2-tailed)	.200	.783	.461	.312	.647	.119	.451	.028

Appendix R.2 - Mann-Whitney: Years of ARVT intake and variables

	CD4+	PSO		Anxiety		Depression		Approach	
Evaluation	**1st**	1st	2nd	1st	2nd	1st	2nd	1st	2nd
Mann-Whitney U	**7**	3.5	2.5	2.5	0	6	2.5	8	0.5
Z	**-.798**	-1.743	-1.83	-1.95	-2.39	-1.24	-1.84	-.573	-2.31
Asymp. Sig. (2-tailed)	**.425**	.081	.067	.051	.017	.216	.067	.566	.021

	Avoidance		Emotional Regulation		Reappraisal		N of Sessions	Years in PSO
Evaluation	1st	2nd	1st	2nd	1st	2nd	-	-
Mann-Whitney U	5.000	10.000	6.000	5.000	7.000	7.500	.500	10.000
Z	-1.25	-.115	-1.04	-1.26	-.800	-.688	-1.27	-.411
Asymp. Sig. (2-tailed)	.210	.908	.299	.207	.424	.491	.203	.681

Appendix S: Psychosocial Intervention Programme Table of content: short 6-sessions version.

Appendix S - Psychosocial Intervention Programme for PLHIV/AIDS
Aaron Cortes PhD Student - Applied Psychology
University of Nottingham

	Presentation	
	Psychosocial Assessment	
First meeting	Social Support Perception, Anxiety by Stress and Depression.	
	Session 1	Session 2
	Depression: Basic information	Conflict solution
	What is depression?	Feelings
	What causes depression?	Plan
DEPRESSION	Depression and behave	Relapse Plan (session 3)
	Session 3	Session 4
	Stress: Basic information	Body reaction to stress
	What is stress?	Relaxation
	What causes anxiety	Interpretation of situations
ANXIETY - STRESS	Treatments – Breathing	Applications
	Session 5	Session 6
	SSP: Basic Information	Confidence play
	What is SSP?	Discussion
SOCIAL SUPPORT	How SSP works?	relaxation
PERCEPTION (PSS)	Groups and identity	Feedback - Farewell
	Psychosocial Assessment	
Assessment post intervention	**Social Support Perception, Anxiety by Stress and Depression**	
AIM The main objective is provide participants with different knowledge in order to face better stressful situations, potentially depressive events and perceptions which may limit social support. Through the utilisation of the most useful techniques regarding personal needs and characteristics, participants are expected to be able to re-interpret their own life situations to achieve better results and reducing interpretations causing conflicts or limiting their abilities.		

Appendix T: Case study Protocol

Format for Case Study Write-Up Protocol

I. Patient profile:

- Age:
- Race:
- Sex:
- Marital status:
- Overview of past clinic visits:
- Chronic illnesses:
- City of residence:
- Occupation:
- Last clinic visit:
- Date

II. Chart Review:

History of Present Illness (HPI)

- Chronology:
- Bodily location:
- Quality:
- Quantity:
- Aggravating or alleviating factors
- Associated manifestations:
- Past evaluations and/or treatment:

Past Medical History (PMH)

- Childhood health:
- Adult health (illness and hospitalizations, surgery, obstetrical history);
- Accidents and injuries;
- Allergies and immunizations:
- Current medications:

Social History (SH)

- Home environment (residence, family relationships);
- Social adjustment (education, work record, military history, community activities, religious activities, friendships, financial status and medical insurance):
- Marital history
- Personal habits (sleep, exercise, diet, smoking, caffeine, alcohol and/or drug use);
- Recent stresses and current supports:

Community Agencies and Resources (CAR)

- Examples of community agencies and resources include Homeless Shelter, Department of Social Services, Home Health Care, Alcoholics Anonymous, The Senior Center, Church, Women's Shelter, and Mental Health Agency.

Review of Systems (ROS) As recorded from most recent medical visit. Examples include:

- General (fatigue, weight change, fever/chills):
- Integument (dry skin):
- Head (dizziness, head trauma):
- Eyes (blurring):
- Ears (pain):
- Nose (discharge):
- Mouth (toothache):
- Neck (swelling):

- Breast (self-exam):
- Respiratory (cough):
- Cardiovascular (shortness of breath):
- Gastrointestinal (constipation):
- Genitourinary (incontinence):
- Genital tract (date of last menses; discharge);
- Musculoskeletal (joint swelling):
- Hematopoietic (easy bruising);
- Endocrine (cold intolerance);
- Nervous system (tremor)
- Psychiatric (depression)

Physical Examination (PE) As recorded from most recent medical visit. Vital signs and other relevant physical findings

Medication: Medications per medical chart to reflect patient's dosage and frequency.

Laboratory Data Include relevant normal values and any abnormal values in recent past, with dates.

Psychological Intervention:

- Opinions during the intervention:
- The most remembered topics:
- Usages after completed:
- Most common strategies used:
- Adaptations of the learned:
- Psychological changes:
- Physical changes:

III. Specific case:

- Immunological records:
- Viral load level records:
- Date of Psychological group intervention:
- Personal experience about PGI
- Anxiety, Depression, Coping strategies and Perceived social support evaluations:

Appendix U: Case report: Semi-structured interview

Semi-structured Interview:

1. Was the intervention helpful?

2. (if 1 yes) In which way the intervention was helpful?
    a. Did have effects in your way to see problems?
    b. Did have effects in the way you see yourself?(in your self-esteem)
    c. Did have effects in the way you behaviour?
    d. Did have effects in how you take care of yourself?
    e. Did have effects in your health status?

3. Why do you think the learned skills are helpful

4. Do you think your personality characteristics made easier for you to understand, use and be beneficed by the techniques included in the programme?

5. Have these learned skills any effects on your environment?
    a. In your house
    b. In your work
    c. Other places?

6. Do you think is there any connection between the rise on CD4+ and the skills learned during the intervention programme?

7. Why so?

Appendix V: Case Report: Questionnaire for demographic data

DEMOGRAPHIC DATA

1	Name					
2	Date of birth					
3	Sex	Masculine		Feminine		
5	How much time ago did you receive your HIV Diagnosis?					
6	What is your highest Educational Level:	Preparatory Education		Post Eighteen Education		
		Uncompleted Primary Education		Uncompleted Undergraduate		
		Completed Primary Education		Completed Undergraduate		
		Uncompleted Secondary Education		Diploma		
		Secondary Education		Master Degree		
		Post sixteen Education		PhD Degree		
7	Who do you live with?					
8	Marital situation:	Single		Married		Widowed	
		Co-Habiting		Separated		Divorced	
9	Do you have any children?	Yes		No		
9a	If yes, How many		**9b**	and do you live together?	Yes		No	
10	What is your occupation?					

11	To what extent is your salary adequate for covering your living needs?	Much less than adequate	Less than adequate	Adequate	More than adequate	Much more than adequate

CD4+ (June)		September	
Viral load level (June)		September	
ARV therapy since			
Time of membership in PSO			

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